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**Exploring how well MidCentral DHB cancer services are
meeting the supportive care needs of their patients
– a mixed method approach.**

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Abstract

Cancer will affect most people in their lifetime, directly or through a family/whānau member or friend. It can have a profound impact on those affected, not just physically, but emotionally, socially, and spiritually. As those affected try to deal with cancer and its treatment, they experience certain needs to help cope with the experience. Supportive care aims to provide the support required to meet these needs. The current study aimed to find out how well MidCentral DHB cancer services are meeting the supportive care needs of their patients, using audit methodology. A mixed-method approach was employed to explore the perspectives of staff and patients. Surveys were utilised with both groups, and interviews were conducted with seven patients to further explore the supportive care needs and unmet needs of this group. The staff survey results found high agreement for having sufficient understanding of patient needs, however, staff were less confident in using tools to identify these needs with patients. Thematic analysis of the staff comments identified one key theme; *constraints*, and three subthemes: *Limits of space and place*; *Important, but not practical*; and *Working within constraints*. Overall, patient survey results found that most believed their needs were well met. Lower agreement was found with patients' psychological, social and spiritual needs being identified and addressed. Thematic analysis of patient qualitative data identified four themes: 1. *People will never forget how you made them feel* (subthemes: *positive interactions*, *just another case*, and *concern for staff*); 2. *Role of family/whānau* (subthemes: *Foundation of support* and *Nuances of support*); 3. *Lack of privacy* and 4. *The importance of communication and information needs across the continuum*. Patients valued the positive interactions they had with staff and the role their family/whānau had in their experience. The other themes highlighted some unmet needs around privacy and communication.

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Table of Contents

Abstract.....	ii
Acknowledgments	iii
Table of Contents	iv
List of Tables	vii
Chapter 1: Background.....	1
1.1 Cancer Burden.....	1
1.2 Cancer Impact	2
1.3 Current Study	3
1.3.1 MDHB Population	3
1.4 Summary and Structure.....	3
Chapter 2: Cancer and Supportive Care.....	4
2.1 Cancer - What is it?.....	4
2.2 Cancer - What causes it?	4
2.3 The Cancer Journey.....	5
2.4 Cancer Symptoms and Impact.....	7
2.5 Quality Cancer Care	8
2.6 What is Supportive Care	9
2.7 Support for Supportive Care	10
2.7.1 Evidence for Supportive Care in Oncology	10
2.7.2 Unmet Needs.....	11
2.8 Patient-Reported Supportive Care Needs.....	12
2.8.1 Informational.....	12
2.8.2 Coordination of Care.....	14
2.8.3 Interpersonal Communication.....	14
2.8.4 Psychological	15
2.8.5 Social.....	17
2.8.6 Family/Whānau.....	18
2.8.7 Spiritual.....	20
2.9 Identifying Supportive Care Needs in Patients	22
2.10 Provision of Supportive Care in New Zealand.....	23
2.11 He Anga Whakaahuru – Supportive Care Framework.....	25
2.12 Current Study	26
Chapter 3: Methodology.....	28
3.1 Reflexivity Statement.....	28
3.2 Methodology	28
3.3 Staff Survey.....	30
3.3.1 Staff Participants	30

3.3.2	Staff Recruitment	32
3.3.3	Staff Survey Design / Procedure	32
3.4	Patient Survey	33
3.4.1	Patient Participants.....	33
3.4.2	Patient Survey Recruitment	36
3.4.3	Patient Survey Design / Procedure	36
3.5	Patient Interviews	37
3.5.1	Patient Interview Participants / Recruitment	37
3.5.2	Patient Interview Design / Procedure	38
3.6	Ethics Approval.....	39
3.7	Analysis.....	39
3.7.1	Quantitative.....	39
3.7.2	Qualitative.....	39
Chapter 4:	Staff Findings.....	42
4.1	Survey Results.....	42
4.2	Qualitative – Thematic Analysis of Comments	45
4.3	Theme: Constraints	45
4.3.1	Limits of Space and Place.....	45
4.3.2	Important, But Not Practical	48
4.3.3	Working Within Constraints.....	50
Chapter 5:	Patient Findings.....	54
5.1	Patient Survey Findings	54
5.2	Qualitative Findings – Patient Interviews	57
5.3	Theme 1: People will never forget how you made them feel.....	58
5.3.1	Subtheme 1: Positive Interactions and Feelings	58
5.3.2	Subtheme 2: Just Another Case	59
5.3.3	Subtheme 3: Concern for Staff	60
5.4	Theme 2: Lack of Privacy	61
5.5	Theme 3: Role of Family/Whānau.	63
5.5.1	Subtheme 1: Foundation of Support	63
5.5.2	Subtheme 2: Nuances of Support.....	64
5.6	Theme 4: The Importance of Communication and Information Needs Across the Continuum.....	66
Chapter 6:	General Discussion	69
6.1	Study Aims.....	69
6.2	General Discussion.....	69
6.3	Suggestions/Recommendations.....	74
6.4	Study Limitations	76
6.5	Future Research.....	76
6.6	Concluding Comments.....	77
References.....		78

Appendix A: Staff Participant Information Sheet	96
Appendix B: Staff Questionnaire	98
Appendix C: He Anga Whakaahuru – Supportive Care Framework. Staff-related standards.....	101
Appendix D: Patient Information Sheet – Questionnaire	102
Appendix E: Patient Questionnaire	104
Appendix F: He Anga Whakaahuru – Supportive Care Framework. Patient-related standards.....	108
Appendix G: Patient Information Sheet - Interview	109
Appendix H: Participant Interview Consent Form	111
Appendix I: Massey University Human Ethics Committee Approval.....	112
Appendix J: MidCentral DHB Research Approval.....	113
Appendix K: Māori Research Review Group Approval.....	114
Appendix L: Breakdown of Likert Responses – Staff Survey	116
Appendix M: Breakdown of Likert Responses – Patient Survey	117

List of Tables

Table 1 Staff Demographic Details	31
Table 2 Staff Role Details	32
Table 3 Patient Demographic Details.....	34
Table 4 Patient Cancer Information	35
Table 5 Interview Participant Details.....	38
Table 6 Staff Survey Results	43
Table 7 Patient Questionnaire Results	56

Chapter 1: Background

1.1 Cancer Burden

There is wide acknowledgement that most people will be affected by cancer in their lifetime, whether directly or through someone they know (World Health Organization [WHO], 2020). With growing numbers of people and an ageing population, cancer incidence (number of new cases) and mortality (number of new deaths) are increasing rapidly. In 2018, there were approximately 18 million new cases of cancer and 10 million deaths worldwide, which are expected to double by the year 2040 (WHO, 2020). Cancer is the second leading cause of death worldwide and is the leading cause of death in New Zealand, where cancer cases are also expected to double by the year 2040 (MOH, 2019a).

Although the burden of cancer is increasing, cancer mortality rates (number per 100,000) are decreasing in some countries, and more people are surviving and living for longer (Sibeoni et al., 2018). Survival in the United Kingdom (those living beyond 5 years after diagnosis) has doubled in the last 40-50 years (Cancer Research UK, n.d.), and the mortality rate for cancer in the United States decreased by 29% from 1991 to 2017 (Siegel, et al., 2020).

Anyone can get cancer regardless of age, social status, or ethnic background; however, lower-income countries will carry most of the burden in the next 20 years (WHO, 2020). Certain differences within higher-income countries are also evident, where these more hopeful patterns are not experienced by all groups (Teng et al., 2017). Mortality rates for most cancer types are disproportionately higher for those with lower socioeconomic status and for those from disadvantaged groups such as ethnic and indigenous groups (WHO, 2020).

New Zealand is no different when it comes to inequalities in cancer. Māori are more likely to be diagnosed with cancer and nearly twice as likely to die from cancer than non-Māori (MOH, 2019a). A range of factors have been identified as contributing to these disparities between Māori and non-Māori such as increased likelihood of comorbidity, deprivation, tumour biology, system-based factors such as poorer access to early detection, availability and affordability of quality treatment, and cultural competencies within the health system (Gurney, et al., 2019). Disparities in New Zealand cancer rates also exist for Pacific peoples compared with non-Pacific, non-Māori (MOH, 2019a), for people living in more socioeconomically deprived areas or in lower socioeconomic positions (McKenzie et.al., 2010; Jeffereys, et al., 2009), and for people with mental illness and/or addiction (Cunningham, et al., 2015).

1.2 Cancer Impact

Cancer can have a profound impact on those affected. Greater numbers of cancer survivors are increasingly continuing to live longer with the consequences of cancer and its treatment, sometimes facing multiple symptoms and challenges even long after treatment is completed (Reilly et al., 2013). Patients can have a wide range of essential needs, for example, the need for information or emotional support (Smith et al., 2015). Some may be able to meet their own needs while others may require further support. Supportive care is the provision of the services needed to meet all the needs someone may have outside of their medical treatment (Fitch, 2008). Meeting these needs is important to help patients and their family/whānau be able to cope with the challenges that come with a cancer diagnosis. The needs of cancer patients and supportive care will be discussed in greater detail in the following chapter.

1.3 Current Study

The number of new cancer cases for MidCentral District Health Board (MDHB) is increasing in number and rate (MDHB, 2017). MDHB want to know how well they are meeting the supportive care needs of their cancer patients and to identify any unmet needs. They have elected to audit their services and want to find out about the experiences and perspectives of the patients who use their services and the staff who provide them.

1.3.1 MDHB Population

Stretching across the middle of the Lower North Island, MDHB covers the following areas: Horowhenua district, Manawatu district, Palmerston North City, Tararua district, and the Otaki ward of the Kapiti Coast District. The population of MDHB is approximately 180,000 most of who live in Palmerston North city. MDHB's population is similar to the national average but has a slightly higher proportion of older people, and higher proportion of Māori, making up just over 20% (MOH, 2019b).

1.4 Summary and Structure

Cancer is a significant health concern both globally and in New Zealand. People affected by cancer have a number of needs to help them better cope with the impact of cancer and its treatment. MDHB want to know how well they are meeting these needs for those who use their oncology services, and to identify any unmet needs. The following chapter will discuss cancer and review the literature on supportive care in cancer. Chapter three will outline the methods used for this research and Chapter four will present the staff results alongside a discussion of the staff findings. Chapter five presents the patient survey results and a discussion of the findings. Finally, Chapter six presents a general discussion and conclusion of both findings, and some recommendations based on these findings.

Chapter 2: Cancer and Supportive Care

2.1 Cancer - What is it?

Cancer is a term used to describe a collection of more than 100 related diseases, characterised by abnormal cells that divide uncontrollably (National Cancer Institute, [NCI], 2015). The body is made up of trillions of cells that form the tissues and organs of the body. Normal cells grow and divide in an orderly way, passing on their genetic material and dying when they become old or damaged (American Cancer Society, [ACS], 2020). The process of dividing and replicating is influenced and controlled by key regulators that help to balance this complex process of encouraging or limiting cell division (Miller, 2018). Cancer is when this delicate balance is disrupted, and cells begin to divide uncontrollably, taking over the normal cells (ACS, 2020). Just as normal cells divide and pass on their genetic material, the abnormal cell also passes on its genetic mutation as it divides, carrying on the unregulated process (Miller, 2018).

There are two main categories of cancer; hematologic (blood cancers) and solid tumour cancers, such as those found in the organs or tissues of the body (ACS, 2020). Tumours are lumps or growths, that can be cancerous (malignant) or not (benign). Unlike benign tumours, malignant growths can invade and affect close-by tissues, or travel to other parts of the body through the blood or lymph system (NCI, 2015).

2.2 Cancer - What causes it?

According to the World Health Organization (WHO, 2020), the genetic mutations involved in cancer are believed to be caused by an interaction between a person's Deoxyribonucleic acid (DNA), and an external agent from three categories. These include physical carcinogens (e.g., ultraviolet radiation), chemical carcinogens (e.g., those found in

tobacco smoke) and biological carcinogens (e.g., infection from virus, bacteria or parasite).

Four major risk factors for developing cancer have also been identified: tobacco use, alcohol use, unhealthy diet and physical inactivity (WHO, 2020). Another important factor associated with the development of cancer is ageing, where the incidence of cancer noticeably rises with age, most likely due to a longer period of exposure to risk factors, and the reduced ability of cells to repair with increasing age (WHO, 2020).

2.3 The Cancer Journey

In the 1800's, there was no known cure, or treatment options available and cancer was therefore associated with imminent death (Holland 2002). Limited understanding of the disease meant that fear, shame and mystery surrounded cancer and those with the disease. But as knowledge of cancer improved and treatments became available in the early 20th century, there was hope for those diagnosed. A move away from the attached stigma occurred as the earliest public messaging about the symptoms, treatment and prevention of cancer attempted to change public beliefs (Holland, 2002).

Cancer care continued to develop with advances in diagnosis and treatment, including therapies commonly used today; surgery, radiation therapy (or radiotherapy), and chemotherapy. Medical advances in diagnosis and treatment produced dramatically increased survival rates and improved quality of care for patients with cancer (Sibeoni et al., 2018). Cancer treatment understandably became the focus of cancer care for some time (Lagergren et al., 2019).

As more people with a cancer diagnosis are living, and living for longer, focus has moved beyond treatment. Greater attention has been given to cancer survivors, the complexity of their experience and the wider cancer journey. The cancer journey is often understood as a non-linear pathway with a number of stages that a person with cancer may go

through. The stages of this journey have been represented in a number of models, for example the Cancer Control (or care) Continuum (NCI, 2020): Aetiology → Prevention → Early Detection → Diagnosis → Treatment → Survivorship and → end of life.

In 1985, a paper was published (Mullan, 1985) by a physician who had had cancer, and felt that the understanding of cancer at the time did not reflect the experience. Historically, when a person completed treatment, they were understood to be ‘cured’ or living with the disease. As ‘cured’ did not seem to capture the effects and ongoing problems he or his patients experienced, Mullan challenged this simplistic understanding and proposed the term ‘survivor’ (Feuerstein, 2007).

Today, a ‘cancer survivor’ has commonly been used to describe a person with a history of cancer who has been in remission for five plus years (Feuerstein, 2007 cited in Cheung & Delfabbro, 2016). However, a cancer survivor is now also understood to be “any person with a history of cancer from diagnosis through the remainder of their life.” (ACS, 2019). The use of the term survivor when used in this study will refer to the latter definition. Survivorship care has become an established, yet varying area of oncology which refers to the journey of living with, through and beyond cancer (Cancer Society of New Zealand, 2018).

While some individuals diagnosed with cancer may still experience cancer as a short-lived experience, cancer has continued to become understood as a more complex disease with a number of unique challenges within and across the different stages of cancer (Aziz & Rowland, 2003). Survivors may move through treatment, between treatments, into long-term survivorship, may experience cancer recurrence, and for some, death will be the final outcome (Fitch, 2008). The disease has increasingly become recognised as a chronic condition needing long-term support and management (Turnbull et al., 2012). An increased

emphasis on the impact on, and care of cancer survivors (Adler & Page, 2008) has meant a move toward a more patient centred, multidisciplinary model of care (Bultz, et al., 2016) to help manage the impact of cancer and its treatment.

2.4 Cancer Symptoms and Impact

Cancer and its treatment can have a significant impact on the affected person and their family/whānau. Cancer survivors can experience multiple acute and chronic cancer or treatment related side effects and symptoms depending on the cancer type and the treatment received (Reilly et al., 2013). Treatment itself can be physically challenging and can cause symptoms such as fatigue, pain, bowel dysfunction, nausea, sexual dysfunction, numbness, tingling and changes to the hair and body (ACS, 2016; Adler & Page, 2008). Cognitive decline is also commonly reported by cancer survivors, with patients experiencing difficulties with memory, concentration, processing speed and executive functioning (Jean-Pierre et al., 2012). Even when treatment is completed and the cancer is gone, survivors can continue to experience lingering cognitive and physical side effects (Burkett & Cleeland, 2007).

The impact of these multiple symptoms on the patient can be described as the ‘symptom burden,’ a concept that refers to the presence and severity of symptoms and the perception of the impact of those symptoms (Burkett & Cleeland, 2007). While symptom burden has been found to decrease over time for individuals (Deshields et al., 2014), increased symptom burden has been associated with poorer quality of life (Deshields et al., 2014) and impaired daily functioning (Dong et al., 2016). A systematic review (Neo et al., 2017) of studies exploring the prevalence of disability related to activities of daily living in cancer patients found that about one third to one half of adults required help to perform basic daily activities, such as personal hygiene and walking. Impairments in physical functioning

causing disability is one of the most common and consistently found causes of distress in cancer survivors (Banks et al., 2010).

In response to, or in addition to these adverse physical and cognitive symptoms, cancer and its treatment can also impact survivors and their family/whānau psychologically, socially and spiritually (Fitch, 2008), which will be discussed in further detail below. The psycho-social-spiritual impact is commonly referred to in the literature as distress, “*a multifactorial, unpleasant, emotional experience of a psychological (cognitive, behavioural, emotional), social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms, and its treatment*” (National Comprehensive National Network, NCCN, cited in Howell & Olsen, 2011, p. 208). Although distress is seen as a normal response, it can range in severity from common feelings of sadness through to depression and anxiety (National Comprehensive Cancer Network, [NCCN], 2020).

Screening for emotional distress became mandatory in oncology clinics in the United States in 2015. The first evaluation of this screening process (which utilised the distress thermometer to measure patient distress levels) was published in 2019 (Carlson et al., 2019), and found that just under half (46%) of patients experienced significant distress. This was not experienced evenly across different cancer types. Screening for distress and responding to the identified needs has been linked to reduced symptom burden (Carlson et al., 2012), improved quality of life (Bultz et al., 2013) and more accurate referrals to psychosocial services (Bauwens et al., 2014).

2.5 Quality Cancer Care

Cancer care is now not only about increasing the number of years lived but improving the quality of life for those affected by cancer. Clinicians have been encouraged to move beyond the bio-medical model to a more patient centred approach that addresses the wider

needs of cancer survivors (Adler & Page, 2008). Patient-centred care acknowledges the needs and values of individuals and meeting these needs has become integral to best practice cancer care (Carrieri et al., 2018).

2.6 What is Supportive Care

Supportive care has been defined as “the provision of the necessary services for those living with or affected by cancer to meet their physical, emotional, social, psychological, informational, spiritual and practical needs during the diagnostic, treatment, and follow up phases, encompassing issues of survivorship, palliative care and bereavement.” (Fitch, 2008, p.11). Supportive care refers to the services or support someone requires during their illness, treatment and during follow up care. It may come from family/whānau, health care providers, religious communities, social groups and even online social media or support groups (Falisi et al., 2017). By addressing these needs, supportive care is essentially helping individuals and their family/whānau to better cope with and manage cancer and its treatment.

The Supportive Care Framework for Cancer (Fitch, 2008) is commonly referred to in the literature and used to guide best practice supportive care policy and guidelines. Originally created in 1994, it was designed as a tool for cancer care professionals to consider and plan for the support patients could need across the cancer journey. Fitch (2008) describes the framework as drawing on key constructs such as human needs, cognitive appraisal, coping and adaptation to understand how humans experience cancer. It recognises that humans are more than physical beings, and that individuals respond differently to life events and have different strategies to cope. The supportive care model (Fitch, 2008) describes the different levels of care that may be required for all individuals diagnosed with cancer. It recognises that all individuals will have some basic needs, and some will require more support than others, highlighting the requirement for tailored care.

When confronted with cancer, an individual's ability to meet their own needs may change, and survivors and their family/whānau may experience a number of practical, psychological, social, spiritual and informational needs to help them to cope (Fitch, 2008). Māori health is commonly understood in relation to Te Whare Tapa Whā (Durie, 1994, cited in MOH, 2017), and also recognises that people are more than physical beings. The model provides four pillars or dimensions of health: physical/tinana, spiritual/wairua, family/whānau and mental/hinengaro. It recognises that the dimensions cannot be separated from each other, and when one is missing or damaged, it can cause ill health. The spiritual, whānau and mental health are as important as the physical dimension to health for Māori (MOH, 2017).

While cancer treatment focusses on the physical, supportive care includes the wider dimensions of health recognised in both Fitch's (2008) and Drurie's (1994) models. It aims to provide the interventions or services required to meet the holistic needs of those affected by cancer, which are unique to the person and changing (Fitch, 2008). Cancer can impact all dimensions of health, either directly, or indirectly through treatment outcomes. Supportive care assumes that this impact can be moderated by certain variables or factors, such as social support. These variables (needs) will be discussed in more detail below.

2.7 Support for Supportive Care

2.7.1 Evidence for Supportive Care in Oncology

While treatment of cancer for the purpose of survival is extremely important, helping patients and their family/whānau reduce or manage the adverse outcomes or symptoms of cancer and its treatment through supportive care has become an essential component of quality care in cancer. Much of the research to date points to improved outcomes for implementing supportive care, noting both its ethical and clinical value in oncology.

Supportive care influences a person's ability to cope with cancer and its treatment. It has been found to reduce severity of treatment related problems (Wagland et al., 2016), improve quality of life (Jordan et al., 2018; Arnaud et al., 2020), reduce treatment side-effects (Scotte, 2012), assist in accurate diagnosis and management (Berman et al., 2020) and reduce unplanned hospital and emergency admissions (Antonuzzo et al., 2017). There have also been a number of clinical trials that have compared cancer treatment alone and cancer treatment alongside care that aims to meet the wider support needs of patients. Outcomes from these clinical trials have shown improved quality of life for cancer patients (Bakitas et al., 2009; Dyar et al., 2012), improved patient understanding (Temel et al., 2011), and improved psychological symptoms for patients and for caregivers who receive wider support (El Jawahri et al., 2017). Further to improved quality of life, some studies have also reported prolonged survival for patients receiving supportive care when compared to routine care alone (Monnery et al., 2018; Basch et al., 2017). One possible reason noted for the results found was the early identification and therefore earlier responsiveness to patient symptoms preventing any further consequences down the track for patients.

2.7.2 *Unmet Needs*

As identified in Fitch's (2008) Supportive Care Model, all patients affected by cancer will have some basic needs, and some will require more complex and ongoing support. A person's ability to meet their own needs may change or be compromised as patients deal with cancer and its treatment, and therefore may require support from others to meet these needs (Fitch, 2008). When these needs are not identified or addressed, patients and their family/whānau can experience unmet needs. Unmet needs are "those needs which lack the level of service or support an individual perceives is necessary to achieve optimal well-being" (Sanson-Fisher et al., 2000). Unmet needs have been identified in 50-66% of patients

at diagnosis and post-treatment (McDowell et al., 2010). Unmet needs vary for different cancer types but have been most commonly found in the physical, psychosocial and information domains (Edib et al., 2016; Harrison et al., 2011; Molassiotis et al., 2017). Cancer survivors can continue to have unmet needs long after treatment has ended (Mazariego et al., 2020).

These unmet needs have been found to be influenced by a number of sociodemographic factors such as age (younger age), sex (female), and income level as well as cancer type and stage (Ellegard et al., 2017; Okediji et al., 2017). Patients' perceived unmet needs are associated with decreased quality of life (Hansen et al., 2012) and reduced physical and emotional wellbeing (Oberoi et al., 2017). Identifying and addressing patients' needs outside of their physical treatment care is therefore important to avoid unmet needs.

2.8 Patient-Reported Supportive Care Needs

There are a wide variety of needs that patients and their family/whānau may have. This next section will discuss some of the more commonly reported patient needs.

2.8.1 Informational

Fitch (2008) describes the information needs of cancer survivors as the need for information to reduce confusion and anxiety and to deliver information that assists in decision making for the survivor and their family/whānau. Examples include information or resources on treatment and side effects, care processes, help with decision making (Fitch, 2008) and any resource specific to the cancer itself or support options available (Central Cancer Network, 2015). The provision of information or educational support for those affected by cancer and their family/whānau is considered an essential component of supportive care in cancer. With a move to more patient-centred care and greater shared

decision making, there is a significant need for the provision of information that is well understood (Manning & Dickens, 2006), is evidence-based, culturally sensitive and relevant (MOH, 2010) to ensure patients and family/whānau can make well informed decisions.

Information needs are commonly reported in supportive care research and suggests that this need is frequently unmet for both cancer patients (Harrison et al., 2009; King et al., 2015, Kotronoulus et al., 2017; Smith & Hyde, 2015), and family/whānau caregivers (Sklenarova et al., 2015). Patients with cancer have a need for relevant and timely information (Walton et al., 2010). Over 80% of participants in a study of more than 2000 cancer patients reported that they wanted all the possible information they might need whether it provided good news or bad news (Jenkins et al., 2001). More informed patients have been found to have higher levels of social, emotional and cognitive functioning as well as lower reported side effects (Schou et al., 2005). Some patients report being dissatisfied with the information they receive though, and this group of survivors have been found to have lower health-related quality of life scores (Lamers et al., 2016) and a higher number of needs and unmet needs when compared to those who were satisfied with the information they received (Rietveld et al., 2018).

While oncologists or specialist health care providers may be the most trusted and main source of information (Shea-Budgell et al., 2014), patients can seek their own sources of information to help inform decision making, with the internet becoming an increasingly preferred option for health-related information (Jiang & Liu, 2020). Information seeking by individuals affected by cancer has increased over time, in line with general population trends (Rutten et al., 2016), and has been associated with better health outcomes in cancer such as on-time preventative cancer screening (Shneyderman et al., 2016) and reduced feelings of anxiety and uncertainty (Stark & House, 2000).

Although many patients want to have as much information as possible, it is also recognised that the amount of information patients want can vary and change throughout the cancer trajectory, suggesting a need for individualised delivery of information. For example, Patients receiving news of prognosis can be in a state of shock and unable to process detailed information at that particular time (Lobb et al., 2011). Some may prefer not to have any further information beyond what is given to them at their consultations and may avoid wanting further information to avoid mental discomfort or to act as a coping tool (Case et al., 2005).

2.8.2 *Coordination of Care*

Cancer is a complex disease where patients may interact with a number of health care providers. Cancer care requires effective coordination of care to ensure patients receive appropriate and timely access to services, to improve patient outcomes and to improve service efficiency (Walsh et al., 2011). The cancer service pathway is recognised as being difficult to navigate (MOH, 2010), and those affected by cancer have a need for support to help them navigate the health system and to be aware of what services are available to them. Continuity of care is important for patients and their family/whānau particularly between transitions, for example waiting for treatment or at end of treatment (Walton et al., 2010). Patients value having a key contact person, effective communication across their health care professionals, delivery of services in a timely manner, and adequate and timely delivery of information (Walsh et al., 2010).

2.8.3 *Interpersonal Communication*

As mentioned above, individuals and family/whānau affected by cancer may interact with a number of health professionals across their cancer journey and will be required to receive and comprehend a considerable amount of information, while also possibly

experiencing some level of distress (MOH, 2010). It is therefore essential for health care professionals to be able to deliver information effectively and in a manner that promotes patient understanding and inclusion in the conversation and decision making. Patient-centred communication is considered an important aspect of quality patient-centred care in cancer and is essential to quality supportive care (Central Cancer Network, 2015). Effective communication and a positive interpersonal relationship with the health professional is also of great importance to patients and family/whānau members (Mazor et al., 2013).

Individuals affected by cancer have a need for sensitive, caring health professionals who provide information in a way they can understand, and who listen and respond to their concerns (Mazor et al., 2013). Qualitative studies exploring patients' perspectives on effective communication have identified a range of communication needs or preferences including the need for health professionals to acknowledge patients' fears and the ability to balance both hope and honesty when communicating information (Stajduhar et al., 2010).

Effective communication between individuals with cancer and their health care professionals impacts positively on a number of outcomes such as recovery, pain management, and adherence to treatment (Fellowes et al., 2004, cited in MOH, 2010). A systematic review of the association between empathy and patient outcomes in cancer using patient perspectives (Lelorain et al., 2012), found that overall, patients' perspectives of empathy in their interactions with health professionals had beneficial effects such as active patient participation, greater satisfaction with care and greater psychological wellbeing.

2.8.4 Psychological

Although many people affected by cancer will cope well and not develop any psychological disorders, cancer and its treatment related symptoms, can cause or worsen psychological and social problems for survivors and their family/whānau (Adler & Page,

2008). Psychological symptoms experienced by cancer survivors can include loss of personal control, major depression and anxiety disorders, issues relating to self-image and body image changes (Fitch, 2008). Depression, anxiety or emotional distress are often reported and reviewed in the literature in the psychological domain. Although rates of depression vary considerably, depressive symptoms are higher in patients with cancer when compared with the general population (Sotelo et al., 2014), and higher rates are often found for women (Linden et al., 2012). A meta-analysis looking at the prevalence of depression, anxiety and adjustment disorder (Mitchell et al., 2011) found that depression affects up to 20% of patients with cancer regardless of where they are in the cancer continuum. Anxiety was found to affect up to 10% of patients with cancer in this meta-analysis but other studies have reported this to be much higher, where clinical or sub-clinical levels were found in approximately 40% of patients (Linden et al., 2012).

The consequences of psychological symptoms or disorders experienced by patients with cancer is also demonstrated in research, where depression has been associated with reduced quality of life, worse treatment outcomes, increased risk for emergency visits, longer stays in hospital and potentially shorter survival. (Mausbach et al., 2020; Rieke et al., 2017; Zhu et al., 2017). The consequences are considerable and furthermore, depression in patients with cancer is often undiagnosed and untreated (Mitchell et al., 2011).

Although much of the literature on supportive care needs and psycho-social oncology explores and identifies the more negative symptoms and outcomes, patients can also experience more positive outcomes, such as post-traumatic growth (PTG), which refers to positive outcomes after a stressful event or positive life change alongside the distress they experience as a result of a cancer diagnosis (Morris et al., 2011). Some research now shows that for some, a cancer diagnosis can be viewed as a catalyst for change or personal growth.

Reported changes after a cancer diagnosis have included a greater appreciation for life, feeling stronger and better able to manage problems, experiencing increased emotional support or closer relationships with family or friends and more empathy for others (Mehdi et al., 2018; Mosher et al., 2017).

There are a number of psychological interventions used to support cancer patients with the range of supportive care needs or symptoms experienced. Research looking into psychological interventions usually refer to or identifies psychological therapies as non-pharmacologic treatments such as psychoeducation, counselling, psychotherapy, mindfulness, cognitive, behavioural or group-based therapy. Factors such as different cancer types, stages and measurement tools used vary widely across studies therefore making it hard to draw conclusions on overall treatment effects. However, much of the previous research does point to an overall positive effect for the use of psychological interventions. Psychological interventions have been shown to reduce cancer-related fatigue (Mustian et al., 2017; Van der Lee & Garssen, 2012), improve pain management/reduce pain (Gorin et al., 2012; Syrjala et al., 2014) and show improvements in anxiety, depression and quality of life (Fors et al., 2010; Guo et al., 2013; Matthews et al., 2016).

2.8.5 Social

The physical and psychological distress experienced by individuals with cancer can worsen and/or create new social problems (Adler & Page, 2008) causing serious disruption to survivors' everyday lives. Cancer survivors may experience challenges with work and employment such as increased risk of unemployment, earlier retirement, a reduced ability to work (Mehnert, 2010), functional limitations (physical or cognitive) at work (Moskowitz et al., 2014) and financial hardship (Altice et al., 2017).

Social needs and support refer to the personal, domestic and financial challenges cancer survivors may need help coping with (Central Cancer Network, 2015). For example, practical assistance with domestic tasks, personal care, personal hygiene, childcare, family support, travel and accommodation, relationship and communication issues, cultural, emotional, employment and income/finance (MOH, 2010). Social support aims to enable survivors to adjust and cope with challenges in these areas through support from clinical and support providers, Māori or Pacific health services, agencies, friends/colleagues and immediate and wider family/whānau (MOH, 2010). Lower perceived social support is associated with higher unmet needs (Lambert et al., 2012) and significantly higher levels of depression and lower quality of life (Eom et al., 2013). Higher levels of perceived social support or network size have been found to be significantly associated with better quality of life (Applebaum et al., 2014) and decreased relative risk of mortality (Pinquart & Duberstein, 2010).

2.8.6 *Family/Whānau*

Family/whānau play an essential role in the lives of those affected by cancer, through social support and by providing a significant amount of the care required by patients (Blum et al., cited in Northhouse et al., 2012). Definitions of psycho-social and supportive care have also evolved to include family/whānau and caregivers who also have a range of supportive care needs themselves.

Support from family and friends is an important coping strategy for cancer patients. As discussed previously in the social domain, increased perceived social support or networks are associated with more positive outcomes. Family/whānau have been described as a source of empowerment for people affected by cancer and have been recognised as the foundation to patients' cancer experience (Egan et al., 2016). A greater sense of empowerment is important

as feelings of loss of control or helplessness are commonly reported in the literature. In research exploring Māori patients' experience with cancer, whānau have been identified as important in providing personal and emotional support throughout the entire cancer journey and also play central roles in providing more practical support. Examples of this include liaising with clinicians and help in making sense of the information received (Slater et al., 2013).

Family/whānau caregivers provide a sometimes-extensive number of care activities across every stage of the cancer journey. These care activities include support with medication, treatments, symptom management and monitoring, coordinating care, practical day-to-day living such as meals or paying bills, communication with health professionals and decision making, navigating the healthcare system to name a few (Given et al., 2012). Given et al. (2012) also note the 24/7 nature of the family/whānau caregiver role, depending on what kind of care or needs are required and that it is a heavily involved role.

It is no surprise then that family caregivers themselves experience challenges and have their own supportive care needs. Supportive care for both patients and their family/whānau is now strongly recommended by organisations in this field including the Multinational Association of Supportive Care in Cancer (Surbone et al., 2010) and the Institute of Medicine (Adler & Page, 2008). Family caregivers often report high levels of psychological distress, depressive symptoms, anxiety, a feeling of burden, exhaustion and sadness, potential burnout, poor health, and unmet social needs (Oechsle et al., 2019; Stenberg et al., 2010), which can in-turn negatively impact the family member being cared for (Sergin et al., 2007). Research findings also indicate that this caregiver stress can lead to psychological and sleep disturbances and affect the physical and financial wellbeing of family/whānau caregivers (Northouse et al., 2012). Although much of the literature in this

area focusses on the challenges or unmet needs for family caregivers, positive aspects of caregiving for cancer patients have also been reported. A critical review of previous research showed that spousal caregivers of cancer patients experienced an enhanced relationship with the person and wider family/whānau, a sense of personal growth and personal satisfaction, as well as feelings of a sense of accomplishment and appreciation for their role (Li & Loke, 2013).

2.8.7 *Spiritual*

Cancer is a challenging and life-threatening disease for those affected, where patients are confronted with the meaning of life and the possibility of death. A diagnosis of cancer can raise spiritual struggles for patients around one's sense of meaning, beliefs, faith, hope and purpose (Puchalski, 2012). Although a significant number of people worldwide identify with a religious group there has been an increased number of people identifying instead as spiritual (Pew Research Centre, 2017) and an increased focus on the relationship between spirituality and health (Shattuck & Muehlenbein, 2020). The spiritual domain has become increasingly understood and recognised as integral to health and wellbeing and has become a valuable part of holistic quality cancer care.

Spirituality can be defined as "... a dynamic and intrinsic aspect of humanity through which persons seek ultimate meaning, purpose, and transcendence, and experience relationship to self, family, others, community, society, nature, and the significant or sacred. Spirituality is expressed through beliefs, values, traditions, and practices" (Puchalski et al. 2014 p. 646). A second commonly used definition for spirituality is: "Spirituality means different things to different people. It may include (a search for) one's ultimate beliefs and values; a sense of meaning; and for some people, religion. It may be understood at an individual or population level" (Egan, 2007; cited in MOH, 2010).

Religion and spirituality (R/S) are recognised as being important for patients coping with cancer (NCI, 2015). Previous studies looking into the spiritual care needs of patients with advanced cancer have indicated a reliance on R/S beliefs (84%) to help cope with cancer (Vallurupali et al., 2012).

Individual studies and meta-analyses of the literature in the last 10 years have reviewed the relationship between R/S and a number of health and cancer-related outcomes. R/S has been found to be associated with better patient reported physical health (Jim et al., 2015), improved physiological markers (Shattuck & Muehlenbein, 2018), improved QoL for patients with cancer (Jafari et al., 2013; Kruizinga et al., 2016;), less aggressive care for cancer patients at end-of-life stage (Balboni et al., 2010), and greater patient satisfaction and perceived quality of care (Wilkelman et al., 2011). Qualitative studies have also provided further insight into patients' understanding of the role of spirituality in their lives. Spirituality has been expressed in relation to family relationships, the meaning of God or a higher being, and some spiritual practices, which have been described by cancer survivors as 'giving strength' and 'activating hope' (Asgeirsdottir et al., 2013).

R/S has been found to play a protective role when it comes to psychological distress, such as depression (Travado et al., 2010). This may be due to a range of variables such as its relationship to physiological benefits, greater social support or its use as a coping resource (Negat et al., 2017).

Lambie et al (2013), recognise that spirituality is particularly critical to providing comprehensive and culturally responsive health care in New Zealand. Spirituality is included in a number of models and guidelines that influence health care/supportive care in New Zealand, for example, Te Whare Tapa Wha (Durie, 1994). Spiritual/Wairua in this context may include relationships and connections with people, the environment, whānau and iwi

where health is seen in a wider context and not in separate parts (Central Cancer Network, 2019).

A pilot co-design project looked to better understand the spiritual care needs of MDHB patients affected by cancer (Egan et al., 2018). The participants' understanding of spirituality was consistent with previous definitions and characterised by values and connectedness with others and/or with the environment, and also through expressions of love and kindness. Another key finding highlighted in this study was the need for spiritual care to be a respected and normalised part of the current health system where there are opportunities to engage in conversations about spirituality. There was also a need and appreciation expressed for sound communication skills, active listening and a kind and gentle nature, also discussed and identified under interpersonal communication needs.

2.9 Identifying Supportive Care Needs in Patients

A number of evidence-based tools have been used to identify the supportive care needs of patients with cancer. The Supportive Care Needs Survey, *SCNS-LF59* (Bonevski et al., 2000, cited in McElduff et al., 2004) is the long version of a screening tool with 59 items covering the following domains; psychological, health system & information, physical & daily living, patient care & support and sexuality. To improve the practical use of the tool, shorter versions have since been developed. *SCNS-SF34* (Boyes et al., 2009, cited in McElduff et al., 2004), contains 34 items covering the same domains. This tool has been assessed and found to be a valid instrument for measuring the perceived needs of cancer patients (Boyes et al., 2009).

Another tool that is validated and widely used is the *Distress thermometer and problem list* developed by the National Comprehensive Cancer Network (NCCN, 2021). Routine screening using the Distress thermometer is recommended by the National

Comprehensive Cancer Network (2021). The Distress Thermometer has also been adapted to better suit the New Zealand context, with the Hauora / Wellbeing Assessment tool.

2.10 Provision of Supportive Care in New Zealand

The provision of supportive care as part of quality cancer care is guided by a number of models, guidelines, programmes, initiatives or strategies. Underpinning all the health-related guidelines and initiatives/programmes in NZ is Te Tiriti o Waitangi (Treaty of Waitangi), the founding document outlining the partnership between Māori and the government and one that acknowledges the need to protect and promote Māori health and wellbeing.

Improved outcomes for individuals diagnosed with cancer have been prioritised by the government with the aim of delivering better and more timely quality health services. The New Zealand Cancer Plan 2015-2018 (MOH, 2014) was a strategic framework guiding a number of cancer-related programmes throughout New Zealand, including the Faster Cancer Treatment Programme (FCT). The FCT programmes focus is to improve the timeline of cancer diagnosis and treatment through specific time targets and also requires DHB's to collect standardised information on patient referrals (MOH, 2018). It also introduced psychosocial care through investment in new work positions (psychologist/social work positions). The more recently developed New Zealand Cancer Action Plan 2019-2029 (MOH, 2019) recognises supportive care as one of its 4-key outcomes to achieve through the plan: "Outcome 4: New Zealanders have better cancer survival, supportive care and end-of-life care –Te huanga 4: He hiki ake i te orange." (MOH, 2019, p.12).

These documents provide a high-level strategic approach but don't provide specific guidance on implementation or integration of supportive care in cancer. In 2010 the Ministry of Health released the *Guidance for Improving Supportive Care for Adults with Cancer in*

New Zealand (MOH, 2010), with the purpose of improving the quality of life for people affected by cancer. The MOH aimed to work with Regional Cancer Networks, District Health Boards and non-government agencies to implement the areas of action in this guidance document. Eight key areas of action and objectives were outlined in this document: 1. Information Support; 2. Interpersonal Communication; 3. Psychological Support; 4. Social Support; 5. Complementary and Alternative Medicine; 6. Support for living Long-Term with Cancer; 7. Spiritual Support and 8. Co-ordination of Support.

This document also provided the rationale for the establishment of the Cancer Psychological and Social Support Initiative (MOH, 2019), where variable access to supportive care services and a gap in psychology and counselling services had been identified. This initiative provides psychological and social support staff and focusses on the time from high suspicion of cancer through to end of treatment at the hospital. These services focus on those with more complex needs who's needs may have not been met within the existing services, those with poorer access to services such as Māori, Pacific, rural or low socioeconomic communities or for specific cancers that are associated with greater distress or less support available.

There has been a recent in-depth evaluation of the Cancer Psychological and Social Support Initiative presented in two reports by Sapere Research Group (Esplin et al., 2018). These reports provide findings from their evaluation of the above initiative from July 2016 to December 2017 utilising a mixed-method approach including interviews, surveys, literature reviews and site visits. Key findings from their evaluation point to the services being invaluable for the majority of patients they heard from, noting that the therapeutic and practical aspects of the services had made a big difference to the lives of patients who used the services. There were also some key recommendations that came from patients, including

wanting to have had earlier access to psychosocial services and wider access to include whānau. From a service point of view, key findings included the ongoing challenge to meet cultural needs, identifying the need to continue identifying and addressing the needs of Māori and Pacific patients and whānau. There were also gaps and variations found in staff education of the services, DHB support for the initiative and resources to meet the growing demand. One particular concern or limitation noted by the researchers was the low rate of feedback, or response for interviews from Pacific people.

2.11 He Anga Whakaahuru – Supportive Care Framework

The first comprehensive supportive care framework in New Zealand was developed in 2015 (Central Cancer Network, 2015), and provides a set of standards/recommendations that act as benchmarks for high-quality cancer care in the implementation of supportive care specifically for cancer. It's designed to be used by government, non-government and private cancer care services to guide service planning and delivery (Central Cancer Network, 2015). He Anga Whakaahuru – Supportive Care Framework (the Framework), is made up of components which are all interlinked and provide support for cancer care services/providers to plan and deliver high quality cancer services.

The Framework is made up of four parts. It provides a model, a visual representation of the components required to provide quality care. The model acts to create a common focus for those using the standards of care (Central Cancer Network, 2015). Another component to this Framework is the standards or competencies, which describe what patients affected by cancer should expect or have access to and provides a benchmark for high quality supportive care services, specifically for cancer. These standards fall under nine key supportive care areas outlined below. These standards cover the same areas as the MOH *Guidance for*

Improving Supportive Care for Adults with Cancer in New Zealand, except for complementary medicine.

1. Foundation standards – which provide the base requirements for all supportive care activities to be provided successfully
2. Interpersonal Communication
3. Information Support
4. Social Support
5. Psychological Support
6. Care and Support Coordination
7. Whānau Support and Involvement
8. Wairua and Spirituality and
9. Living with and Beyond Cancer.

Each section also provides workforce competencies to match the standards to ensure staff have the information and skills required to provide quality supportive care. The last component of the framework is a quality tool and checklist to provide considerations to evaluate, adapt or develop resources.

2.12 Current Study

Cancer survivors and their family/whānau have a wide range of needs outside of their treatment. There is strong encouragement for the integration of supportive care in cancer, in both its ethical and clinical value, but some research shows that this has not happened (Carrieri et al., 2018). For those services that have made the decision to implement best practice supportive care guidelines into routine oncology care, the question moves from, why

integrate supportive care to - how well are these recommendations being integrated into routine cancer care and how well are they meeting the supportive care needs of patients and their family/whānau?

MDHB, Palmerston North Hospital want to know how well they are meeting the supportive care needs of their patients and their family/whānau and have elected to audit their services against a set of recommendations set out in the Framework (He Anga Whakaahuru – Supportive Care Framework). Four sources of data were identified to collect the information needed for this audit: Patient records; hospital policies and procedures; staff perspectives; and patient perspectives. To ensure patient or hospital details were not shared outside of MDHB, it was agreed that reviews of the first two data sources would be carried out internally.

This current study looks to explore the perceptions and experiences of the patients/consumers of the cancer services provided by MDHB, Palmerston North Hospital. The provision of supportive care services is dependent on staff, therefore, this study also looks to explore the perceptions of staff/service providers. This research seeks to answer the following questions:

1. Do MDHB staff feel confident and supported to meet the supportive care needs of their patients?
2. How well do patients of the cancer care services at MidCentral DHB, Palmerston North Hospital feel that their supportive care needs have been met?

Chapter 3: Methodology

3.1 Reflexivity Statement

Reflexivity requires myself, the researcher, to be sensitive to the ways in which my own experience may influence the data being collected and created in this study. To engage in this practice is to also acknowledge my own subjectivity in this process (Braun & Clarke, 2020). I understand that the way in which data is collected, interpreted and presented, can be influenced by certain factors both internal and external.

I am female and of mixed ethnicity both Samoan and New Zealand/European. I had not had a close relationship with someone with cancer until a couple of years before starting this research. I witnessed the tough, raw and emotional side of cancer, but at the same time felt the connection and support from, and among, other patients, their family/whānau and hospital staff. This research used a structured framework to guide the questions in the survey, which reduced any influence of my previous experience on the development of questions. However, I hoped that this previous experience gave me greater empathy and understanding in my interactions with interview participants and helped them to feel comfortable in sharing their journey.

3.2 Methodology

The research questions were answered using clinical audit methodology. Clinical audit provides a quality improvement tool or strategy for reviewing patient care or practices against already well-defined standards or criteria (Esposito & Canton, 2014). The following steps make up the clinical audit cycle (Naveen et al., 2011; Benjamin et al., 2008): *1. Choose the audit topic / plan / prepare for the audit; 2. Identify best practice or standards to be used;*

3. Data collection; 4. Data analysis; 5. Implement changes / recommendations; and 6. Check improvements / re-audit.

The Framework was created as a resource for cancer services in New Zealand to guide the delivery of supportive care. It outlines best-practice standards for what is believed should be integrated into practice to meet the supportive care needs of patients and family/whānau affected by cancer. The needs identified in the previous chapter are encapsulated in this Framework, which has been used as a structure for this study to explore how well the needs of patients and their family/whānau are being met.

Patient satisfaction is one of the most important outcome measures in quality improvement projects (Rapport et al., 2019), and is positively associated with clinical effectiveness and patient safety (Doyle et al., 2013). This study used a mixed-method approach to understand and capture the perspectives of staff and patients. Questionnaires were utilised to collect both quantitative and qualitative responses from staff and patients to answer the research questions. Questionnaires aimed to find the degree to which staff felt confident and supported to meet the supportive care needs of patients, and the degree to which patients felt that their supportive care needs were met. To learn more about the met and unmet needs of patients, semi-structured interviews were also conducted with patients. Utilising both methods in this study enabled data to be collected that was able to answer the research questions using a structured framework, while also providing further context and insights. Patient interviews gave participants the opportunity to give detailed descriptions of issues that were important to them (Evans, 2017), and to identify any unmet needs not picked up on in the surveys. The methods used will be described in three sections in the following order: staff survey, patient survey, and patient interviews.

3.3 Staff Survey

3.3.1 Staff Participants

All current Cancer Screening, Treatment and Support (CSTS) Services staff employed by MDHB were invited to participate. Non-MDHB employees working at Palmerston North Hospital were excluded from this study. There were 206 CSTS staff at the time of this research of which 42 completed the survey. Participant details are outlined in Table 1 and Table 2. The majority of staff participants identified as female (97.7%) and were aged between 18 and 74 ($M=43.2$, $SD=13.43$). Females made up 84% of staff in this service at the time of this research, so it is not completely surprising that almost all participants were female. Most participants worked in treatment services (79.1%) and just under half (46.5%) were Allied Health workers, which includes radiation therapists. The majority of participants identified as NZ/European (85.7%) or Other (16.7%). The percentage of Māori (9.5%) participants was slightly higher than the percentage of total Māori MDHB staff (approximately 6%). Participants who identified as 'Other' listed the ethnicity they belonged to as 'British' ($n=2$) 'European' ($n=2$), 'Asian' ($n=1$), and 'Scottish' ($n=1$).

Table 1*Staff Demographic Details*

Factor	<i>n</i>	%
<i>Gender</i>		
Male	1	2.4
Female	41	97.6
Total	42	100
<i>Age</i>		
18-24	2	4.9
25-34	12	29.3
35-44	8	19.5
45-54	9	22.0
55-64	8	19.5
65-74	2	4.9
75+	0	0.0
Total	41	100
<i>Ethnicity</i>		
NZ / European	36	85.7
Māori	4	9.5
Samoan	1	2.4
Cook Island Māori	0	0.0
Tongan	0	0.0
Niuean	0	0.0
Chinese	0	0.0
Indian	0	0.0
Other*	7	16.7
Total**	48	

* 'other' option was followed by a comment box to type their ethnicity.

** Participants were able to choose more than one option.

Table 2*Staff Role Details*

Factor	<i>n</i>	%
<i>Area of work</i>		
Screening	1	2.4
Treatment	33	78.6
Support	8	19.0
Total	42	100
<i>Role</i>		
Administration	2	4.8
Receptionist	1	2.4
Doctor	6	14.3
Nurse	11	26.2
Allied Health	19	45.2
Other	3	7.1
Total	42	100

3.3.2 Staff Recruitment

An email was sent to potential participants in the form of a ‘newsflash’ email as recommended by MDHB’s Audit and Service Development Coordinator. It was agreed that this email would come from the Operations Executive for CSTS services. The email invited participants to take part in the study and contained a link to the anonymous online survey.

3.3.3 Staff Survey Design / Procedure

Staff participants were presented with an information sheet (see Appendix A) with details of the study before being able to complete the survey. The staff questionnaire (see Appendix B) contained two main sections and was designed to meet the staff-related standards in the Framework (see Appendix C). The first five questions collected demographic

data about the participants. The second section contained 12 4-point Likert-scale statements related to the standards in the Framework, for example, *“Please choose the answer that best describes how much you agree with this statement: When I interact with a patient, and their whānau we have enough time scheduled to discuss what is important to them.” “Agree, Somewhat Agree, Somewhat Disagree, Disagree.”* This question was designed to assess standard 2.1: *“Within service delivery, appropriate time is scheduled to allow for full discussion, with the patient and their whānau about what matters to them.”*

A comment box was available after each question for participants to elaborate on their answer if they wished. The Online survey was open for four weeks from the date the email was sent to staff (17 August 2020) with a reminder email sent two weeks before closing (31 August 2020).

3.4 Patient Survey

3.4.1 Patient Participants

All MDHB patients diagnosed with cancer in 2019 and who had received treatment were invited to take part in this study. This study restricted participants to those diagnosed in 2019 to ensure that the experiences were recent and that participants were likely to have already received treatment. Participants needed to be 18 years or older and have a listed email address. According to data provided by MDHB, there were 539 new cases of diagnosed cancer in 2019. Of the 539 cases, 34 did not receive treatment, one person had been given two cancer diagnoses, 105 people had since died, and 153 people had no recorded email address, which left 246 potential participants. Thirty Participants completed the patient survey, and their details can be found in Table 3 and Table 4. Of the 30 participants who completed the survey, 16 identified as female, 13 as male and one as other. All participants were aged 35 and over ($M=63.5$, $SD=12.8$) and identified as NZ/European (80%), Māori

(10%) and Other (13.3%). The ‘Other’ category included a comment box and included ‘New Zealander’ ($n=2$), ‘American’ ($n=1$) and Irish ($n=1$).

Over half of the participants had been diagnosed with either breast (26.7%) or prostate (26.7%) cancer. Breast and prostate cancer are the two most common causes for malignant cancer registrations for MDHB and New Zealand (MDHB, 2018). The majority of the remaining participants chose the ‘Other’ option (40%) and listed diagnoses such as ‘Bladder’ and ‘Melanoma’. The majority of participants had experienced surgery (83.3%) services and over half had received radiation therapy (53.3%) services.

Table 3

Patient Demographic Details

Factor	n	%
<i>Gender</i>		
Male	13	43.3
Female	16	53.3
Other	1	3.3
Total	30	100
<i>Age</i>		
18-24	0	0.0
25-34	0	0.0
35-44	3	10.0
45-54	4	13.3
55-64	8	26.7
65-74	8	26.7
75+	7	23.3
Total	30	100
<i>Ethnicity</i>		
NZ / European	24	80
Māori	3	10

Factor	n	%
Samoan	0	0.0
Cook Island Māori	0	0.0
Tongan	0	0.0
Niuean	0	0.0
Chinese	0	0.0
Indian	0	0.0
Other	4	13.3
Total*	31	

**Participants were able to choose more than one option*

Table 4

Patient Cancer Information

Factor	n	%
<i>Diagnosed by</i>		
Screening	9	30.0
General Practitioner	12	40.0
Emergency Department	1	3.3
Other	8	26.7
Total	30	100
<i>Cancer Type</i>		
Lung	2	6.7
Bowel	4	13.3
Breast	8	26.7
Prostate	8	26.7
Uterine/Ovary/Cervix	0	0.0
Other	12	40.0
Total*	34	
<i>Services Experienced</i>		
Surgery	25	83.3
Radiation	16	53.3
Chemotherapy	7	23.3

Factor	n	%
Palliative Care	4	13.3
Total*	52	

*Participants were able to choose more than one option.

3.4.2 Patient Survey Recruitment

Potential participants were sent an email from MDHB. This ensured that there was no need to share patient contact details outside of the hospital. The email explained the aim of the study briefly and provided a link to the anonymous online survey. Māori recruitment and participation were discussed with MDHB's Equity and Bicultural Practice Programme Lead, who also consulted her colleagues at Pae Ora Māori Health. Limited access to devices and the internet was considered a possible barrier to Māori participation. The use of paper questionnaires sent via post to all potential participants was considered but would have required high printing and postage costs. To increase Māori participation, it was recommended that Māori Cancer Coordinators – Kai Manaaki Mate Pukupuku (MCC's) engage with Māori patients and share paper copies of the survey for those who may not have received the email.

3.4.3 Patient Survey Design / Procedure

Participants were presented with an information sheet (see Appendix D) before being able to complete the survey. This information sheet contained details of the study, what to expect, any risks or benefits, and provided support details should any participants had felt that completing the survey caused any distress or discomfort. The patient questionnaire (see Appendix E) contained two main sections. The first seven questions collected demographic data, for example age and cancer diagnosis.

The second part of the questionnaire was designed to collect information related to the standards in the Framework (see Appendix F) and used 15 4-point Likert scale statements. For example, *“Please choose the answer that best describes how much you agree with this statement. “I was involved in my treatment and care decisions” Agree, Somewhat Agree, Somewhat Disagree, Disagree.* This was one of the questions designed to address the following standard: standard 2.1: *“The person affected by cancer and their whānau are involved with treatment and care planning by all agencies.”* Participants were able to add comments to express any further thoughts about each statement if they wished.

The survey was open to complete from the date the email was sent (17 August 2020) and remained open for four weeks, and a reminder email was sent at the midway point (31 August 2020). Paper copies of the questionnaire, participant information sheets, and a pre-paid return envelope were given to the four MCC’s who covered different locations under MDHB to share with the patients they worked with. One paper copy of the survey was returned.

3.5 Patient Interviews

3.5.1 Patient Interview Participants / Recruitment

All patients who completed the survey were given the opportunity to participate in an individual interview. Once participants had completed the online survey, they were asked if they would be interested in finding out more about participating in an interview with the researcher. If the participant clicked yes, they were automatically taken to a separate page, where they were presented with a copy of the interview participant information sheet (see Appendix G). This contained details about what to expect, and any potential risks or benefits. Participants were then able to indicate if they would be interested in being contacted to

participate in an interview. MCC's also discussed the interviews with the patients they worked with.

Eleven survey participants indicated that they would be interested in participating and a further two were referred through an MCC. Seven interviews were able to be organised from this group. Table 5 outlines the interview participants' details.

Table 5

Interview Participant Details

Name*	Gender	Cancer location	Ethnicity
Frank	Male	Prostate	NZ/European
James	Male	Bladder	NZ/European
Kaha	Male	Prostate	Māori
Laura	Female	Breast	NZ/European
Mere	Female	Other	Māori/NZ European
Shaun	Male	Neck	NZ/European
William	Male	Prostate	NZ/European

**Alias names have been used.*

3.5.2 Patient Interview Design / Procedure

Participants who indicated their interest in participating in an interview were contacted by the researcher to see if they were still interested. Participants were able to choose to participate through video call, phone call or in-person. One interview was a video call, three were phone calls and three were in-person interviews that took place in Palmerston North. One was held at a café chosen by the participant, and one at a participant's workplace in a private room. The other in-person interview took place with a participant and their MCC at an address organised by the MCC. This particular interview was more of an informal

conversation and was not audio recorded. Notes were written down during the interview and were followed up at a later date with the participant to check for accuracy.

Before interviews started, the researcher checked to see that each participant understood the patient information sheet and was given the opportunity to ask any questions. Participants were asked to sign a consent form (see Appendix H) or to email that they agreed to participate and for interviews to be recorded. Interviews were audio recorded and later transcribed. Participants had the opportunity to review their transcripts, one participant asked to do this and returned the edited version by email. Interviews were up to an hour and participants received a \$30 voucher for their time.

3.6 Ethics Approval

A full ethics application was submitted, and approval granted by the Massey University Human Ethics Committee (Appendix I). This research was also approved by the MidCentral DHB Research Support Office (see Appendix J) and endorsed by MidCentral DHB Māori Research Review Group (see Appendix K).

3.7 Analysis

3.7.1 *Quantitative*

Closed-ended survey questions from both staff and patient questionnaires were analysed using The Statistical Package for Social Sciences 26 (SPSS 26) to report basic descriptive statistics, such as measures of frequency and percentages.

3.7.2 *Qualitative*

Data from individual interviews and comments from the questionnaires were analysed using Thematic Analysis (TA) to make sense of the data collected. Comments from

individual survey questions were also used to illustrate or add context to the quantitative data. TA was chosen for this research to identify any key patterns or perspectives from the stories shared by participants. This study was designed to answer a research question based on a pre-existing framework. A deductive, semantic approach was employed to carry out the TA process, and the analysis of interviews followed the steps outlined in the systematic framework for TA by Braun and Clarke (2006).

3.7.2.1 Familiarisation of the Data

Interviews were conducted with the researcher. Once interviews were completed, the audio was listened to and transcribed by the researcher. The transcribed interviews were then read to become familiar with the transcripts.

3.7.2.2 Coding the Data

The qualitative data was manually analysed. Transcripts and survey comments were copy and pasted into an excel spreadsheet and read multiple times to identify and create codes in the column alongside the transcript. The codes created were identified based on their relevance to the research question.

3.7.2.3 Searching for Themes

Once the lists of codes were generated from the staff and patient surveys and interviews, they were analysed and combined to form groups of similar and recurring ideas, both within survey questions and across the whole data set. The codes and initial themes related to Māori were discussed with MDHB Equity and Bi-cultural Programme Lead, and a Massey University Senior Clinical Psychologist, Ngāti Porou. The data related to Māori was discussed to ensure any interpretation as non-Māori was not going to cause any further harm to Māori, through their experiences with research and the health care system. Mind maps

were created to start visually grouping codes into possible themes. A sample of transcripts with codes and possible themes were cross-checked by the researcher's supervisor.

3.7.2.4 Reviewing Themes

Coded data was reviewed to consider how the codes worked together to create meaning. The transcripts were re-read to see how the thematic map fit with the data.

3.7.2.5 Defining and Naming Themes

Themes were defined by exploring what each theme captured, and why it was of interest. This process involved renaming some groups to better reflect the essence of the data.

3.7.2.6 Producing the Report

The findings and discussion of these findings are presented in the following two chapters.

Chapter 4: Staff Findings

4.1 Survey Results

The quantitative survey results are presented first with comments from the free text boxes added to provide further context to the questions. This will be followed by the findings and some discussion of the analysis of staff comments. The summarised quantitative results of the staff survey are presented in Table 6. A table with a breakdown of Likert-scale responses can be found in Appendix L. Overall, most participants agreed or somewhat agreed (referred to now as agreement) with each statement. There was a high level of agreement (95%) for knowing when and how to access interpreter services. Staff reported that they felt confident accessing interpreter services, although some comments showed more of a confidence in being able to find out if there was a need for one rather than knowing the actual process.

“I can follow documentation though and figure I could figure it out.”

“I haven't use them for a long time, but can find out if I need them.”

“I currently have no idea how to order interpreter services. I would have to investigate on the Midcentral portal on how to arrange this if required.”

There was also high agreement with staff having sufficient understanding of the impact of both the psychological (97.6%) and social (90.2%) needs on patients and family/whānau. However, staff were less confident in knowing how to use evidence-based tools or screening methods to assist in identifying psychological (71.8 % agreement) and particularly social (56.4 % agreement) needs. Although the majority of participants agreed with knowing the impact of both needs, multiple staff noted in the comments that it was

Table 6*Staff Survey Results*

Question	Agree OR Somewhat Agree % (n)	Somewhat Disagree OR Disagree % (n)	Total N
1. The environment in which I interact with patients meets their privacy needs.	69.0 (29)	31.0 (13)	42
2. The environment in which I interact with patients meets their cultural needs.	66.7 (28)	33.3 (14)	42
3. When I interact with a patient, and their whanau we have enough time scheduled to discuss what is important to them.	70.7 (29)	29.3 (12)	41
4. I have the required experience and skills to handle difficult conversations (such as giving bad news).	77.8 (28)	22.2 (8)	36
5. I am supported by MidCentral DHB to reflect on situations of difficult communication.	57.9 (22)	42.1 (16)	38
6. I know how to use / access interpreter services if required.	95.1 (39)	4.9 (2)	41
7. I have sufficient understanding of the impact of social needs on my patients and their whanau.	90.2 (37)	9.8 (4)	41
8. I know how to use evidence-based tools or screening methods to assist in identifying and clarifying social needs of my patients.	56.4 (22)	43.6 (17)	39
9. I have sufficient understanding of the psychological impact of cancer on my patients and their whānau.	97.6 (40)	2.4 (1)	41
10. I know how to use evidence-based tools or screening methods to assist in identifying and clarifying psychological needs of my patients.	71.8 (28)	28.2 (11)	39
11. There is a culture of whānau inclusion in services provided to our patients.	90.2 (37)	9.8 (4)	41
12. Systems are in place to ensure patients and their whanau are fully informed of their right to be cared for in a manner which is in agreement with their spiritual beliefs.	89.5 (34)	10.5 (4)	38

“difficult” or “impossible” to fully understand the psychological and social impact and needs of patients. Comments in the current study further highlighted the uncertainty in this area particularly with identifying social needs citing for example a “lack of training”, not knowing how to refer, and an acknowledgment that staff are “learning more” in an area that is “...often overlooked...” Staff reported being interested in learning more about identifying and clarifying the psychological and social needs of their patients, “...we have some resources, but I'd like to know more”, “I would like to learn more.”

There was also strong agreement (90.2%) with there being a culture of whānau inclusion in the services provided. Participants’ comments for this question pointed out that staff tried their best or that there was “attempted inclusion” of whānau. Although there was an acknowledgement of improvement in this area, staff reported certain factors that did not support this, such as lack of time and space, which will be discussed further below.

Lower levels of agreement were found with the environment meeting the privacy or cultural needs of patients. Approximately 30% of participants did not think that the environment met the privacy or cultural needs of their patients, often referring to limited space. Comments again highlighted staffs’ perception of an improvement in the environment meeting the cultural needs of patients, however also acknowledged challenges in meeting this need. Nonetheless, staff still showed interest in further improvements to create a more culturally friendly environment, “Would love to have a Wairua bowl at entrance/exit of the department or treatment units for patients and whanau.” Multiple comments also conveyed that cultural training was limited and suggested that other cultures’ needs (other than Māori) were not considered.

One of the lowest levels of agreement (57.9%) was found with the statement “I am supported by MidCentral DHB to reflect on situations of difficult communication.”

Comments described having no support in this area and staff finding support among colleagues to meet this need. This statement is discussed further in the qualitative section below.

4.2 Qualitative – Thematic Analysis of Comments

Similar ideas became evident across comments in the different survey questions. The following major theme and subthemes were identified to capture the over-arching elements and patterns found in the data. Most of the key ideas that came through in the comments were related to the one identified major theme: *constraints* or limitations that staff felt they had on their ability to meet the needs of patients. Three subthemes were identified in the data and are outlined below:

Theme: Constraints

Subtheme 1: Limits of Space and Place.

Subtheme 2: Important, but not practical.

Subtheme 3: Working within constraints.

4.3 Theme: Constraints

4.3.1 Limits of Space and Place

Comments relating to the limits of space and place formed a strong pattern found across many of the supportive care areas in the survey. Staff often acknowledged that although particular areas of care were important to them, that it was not always practical or possible with the spaces they were working in. Comments associated with space and place

were found to relate to the physical room itself; not enough private spaces available; and the location or proximity of spaces.

The physical make-up of the room often referred to rooms being too small to meet the needs of patients with wider family/whānau:

“the clinic room I use is too small for patients to bring more than 1 support person with them”

“The clinic rooms are small and it can be difficult to have patients and their whanau in a room that feels comfortable for conversations that relate to bad news”

“Something we try and do as a department, but can be challenging i.e. small interview rooms...”

“Although we try to always include whanau many of our spaces (clinic rooms, bed rooms) are small and not conducive to more than 1-2 whanau supporting the patient at one time.”

“However it is almost impossible to have large whanau meetings in our current rooms”

Another physical aspect of spaces and places highlighted in the data was the material environment of the rooms. Participants discussed the material aspects of rooms and how it did not meet the privacy needs of patients:

“We have conversations with people and their families with cancer in open spaces, or in clinic rooms which have very thin walls”

“Sometimes if doors are broken or admin staff aren't there occasionally the privacy can almost be breached”

“Our rooms are not well soundproofed, there is lots of environmental noise, making it even more difficult sometimes to have hard conversations.”

This last comment highlights how “thin walls” can mean a lack of privacy for the patients and family/whānau, but at the same time, make the conversations happening inside the rooms more difficult when having to compete with outside noise.

The environment or set up of rooms was also described and referred to shared rooms with limited privacy and a clinical feel to the spaces.

“Privacy can be an issue for patients in shared rooms.”

“As best as able in four bedded rooms with curtains for privacy.”

“...and spaces are very medical”

“Treatment areas are often shared spaces and conversations about diagnosis and treatment plans are made with patients behind curtains. Although this gives the sense of privacy, the reality is there is sensitive information that is over-heard by other patients in the treating area. It does cause a lack of privacy for patients and their medical information.”

This last comment is interesting in that it not only points out the lack of privacy with shared rooms separated by curtains, but that these curtains create a sense of privacy. However, in reality, sensitive information can be overheard by other patients and staff in the rooms, suggesting a false sense of privacy for patients and their medical information. Patients

also described feeling a lack of privacy in shared rooms with curtains and will be discussed in the patient findings.

A lack of private spaces available or the need for more private spaces to meet the needs of patients particularly when having conversations was also reported. The location or proximity of these private spaces to other areas was also touched on.

“Would be nice to have more private rooms closer to the treatment units that were sound proof or not directly off main corridors.”

“...it can be difficult to find a private space to have discussions with patients.”

“Need more private rooms to talk with patients away from public or staff only areas.”

A lack of available private spaces was not only a concern for privacy with conversations but for patients during treatment:

“No private space for patients to wait once changed, others can see how they are dressed, what area is being treated.”

Space and place are intertwined and meaningful in its relevance to multiple patient needs, for example privacy in conversations and treatment, and in creating an environment that meets cultural needs such as having enough space for wider family/whānau.

4.3.2 Important, But Not Practical

The second sub-theme captures the juggle to find a balance between wanting to, or trying to meet patient’s needs, while also needing to work with other demands or limitations. Participants tended to acknowledge the importance of meeting, or trying to meet certain needs, but in addition to this, gave reasons for why needs could not always be met. It is

evident from the data that busy workloads, not enough staff, and limited time, were significant to how staff felt they were able to respond to the needs of patients while at the same time trying to run an efficient service. The following quotes capture the essence of this sub-theme:

“Sometimes patients have extra needs and it would be nice to have the support of extra staff and more private whanau rooms to be able to discuss these without time pressure (i.e. before or after a procedure) so as not to hold up other patients or feel dismissive if trying to catchup.”

“...Unfortunately there is never enough time to complete all the required tasks. Treating areas are often understaffed and we are pulled to cover these roles rather than working in our own areas...although health professionals strive towards trying to discuss all the patient needs, the reality is we are already having to think about the next task, the next patient due to the restricted time and resources allocated to each individual patient.”

“Discussions are increasingly complex, difficult and distressing. A lot of key information is required to be given...ideally each patient would have two opportunities for discussion prior to each treatment decision. this is currently impossible.”

The quote above describes conversations becoming *increasingly* complex, difficult and distressing. The participant gives an example of an ideal solution to help address this but points out that it would be “impossible”. This quote also highlights the importance for staff to feel supported to reflect on situations of difficult communication.

One participant gave examples of how staff are trying to meet the cultural needs of patients, by trying to use te reo Māori and encouraging the inclusion of whānau at appointments. This participant also considered the wellbeing of patients' family/whānau, but again, acknowledged the difficulty in doing this with busy workloads and short staff numbers.

"We are trying very hard to move towards this - using Maori language around our department, encouraging support people/whanau to attend appointments and treatments and discussing support people's/whanau wellbeing too. this can often be hard on a busy day with short staff numbers and everything else which happens..."

Time, workload, space and staff numbers were all frequently reported factors that limited staff's ability to meet patients' needs. The following quote also highlights the juggle of trying to meet patients' needs within these constraints, but interestingly also points out the need to consider the hospital's policies and how it may affect patients' needs:

"We also have local policies around having support people in the room for a patient's first treatment to help reduce distraction for staff with extra checks - this can sometimes be distressing to patients who value their whanau involvement. We try to be flexible in these scenarios but can be challenging with high workload, busy days, not enough staff to support etc."

4.3.3 Working Within Constraints.

The previous sub-themes highlight the constraints that staff see affecting their ability to meet patient's needs. An interesting idea further identified in the data was how staff were managing or navigating their everyday work despite these limiting factors. When staff added comments in response to a question and discussed difficulty in meeting certain needs, it was

sometimes followed by an explanation or description of what this meant for the way in which they worked.

When some conversations were complex and time limited, staff were running late or working late to try and give their patients the time they needed:

“We don't often have the scheduled time and will often run a bit late if there is more that needs to be discussed.”

“...if something arises we will often prioritise that patient's needs and run late...”

“We make time as much as we can. Often very busy workload. Will work late to ensure this is met as much as possible.”

When there were not enough staff, one participant described needing to cover other roles.

“Treating areas are often understaffed and we are pulled to cover these roles rather than working in our own areas.”

With limited private spaces available, staff described having conversations on the move or in public spaces where other patients and staff could hear:

“We often ask patients how they are, or if they are experiencing issues or if their bladder is full etc while in the waiting room or while walking them into the room and I'm sure other patients can hear.... am aware that sometimes this is not ideal and sometimes you may not get a fully honest answer from patients because they may feel exposed.”

Staff also commented on how rooms were being used when spaces did not accommodate extra family/whānau.

“If patients come with a number of supportive whanau, some often have to sit on examination beds.”

Staff found ways to improve the clinical feel of the spaces available.

“The outpatient environment tries to support cultural needs with imagery”

“We have tried to make the department space less institutional with art work and pictures.”

As mentioned in the previous section, the survey showed one of the lowest levels of agreement for staff feeling that they were supported by MDHB to reflect on situations of difficult communication. When this was not supported, staff discussed finding support themselves often through their work colleagues to meet this need.

“Not as much support as there could be, and very much driven by the individual rather than the organisation”

“There is no specific support provided by the DHB for this. I am supported by my colleagues to reflect.”

“we don't have organized supervision or times organized for reflection it is generally ad hoc which I find inadequate. You often end up using your colleagues that are friends as well to debrief.”

The thematic analysis of qualitative data has provided a richer description of concerns and context that was not captured in the closed-ended questions in the survey. The key

themes highlighted how staff were able to, or less able to meet the supportive care needs of patients and their family/whānau, which also gives another perspective to how well MDHB are meeting the supportive care needs of their patients.

Chapter 5: Patient Findings

5.1 Patient Survey Findings

The quantitative survey results are presented first with comments from the qualitative data used to provide further context to the questions. This is followed by the findings from the thematic analysis of the qualitative data. The summarised quantitative results of the survey can be found in were assessed and addressed throughout their care. The few comments to these questions gave mixed responses where one participant described having not discussed any wider support, *“Other than being aware of the cancer society support if required, nothing else was discussed.”* Whereas a couple of others had evidently received some support and found it valuable. *“Regular sessions with a psychologist were extremely important and helpful in coming to terms with my situation.”* *“Being referred promptly for counselling was very reassuring and consoling.”*

A further breakdown of Likert scale responses can be found in Appendix M. Overall, there was very strong agreement by patients with the statements in the survey. One hundred percent of participants who answered the first two questions felt that they, and their family/whānau were able to be involved in their treatment and care decisions. Most participants agreed or somewhat agreed that the place in which they had conversations met their privacy (93%) and cultural (94%) needs, although some privacy concerns were reported in the comments or interviews, which will be discussed in the next section.

Although still strong agreement, a lower percentage of participants felt that their social (82% agreement), psychological (76% agreement) or spiritual (81% agreement) needs were assessed and addressed throughout their care. The few comments to these questions gave mixed responses where one participant described having not discussed any wider

support, *“Other than being aware of the cancer society support if required, nothing else was discussed.”* Whereas a couple of others had evidently received some support and found it valuable. *“Regular sessions with a psychologist were extremely important and helpful in coming to terms with my situation.” “Being referred promptly for counselling was very reassuring and consoling.”*

Some patients also felt that on reflection, being able to talk to someone about how they were coping would have been helpful *“Maybe at the start or the middle, once you understand a bit more, if someone had spoken to me more about what was happening to me and how I would cope with it, might've helped.”* The mixed responses suggest that screening for psychological, social or spiritual needs may not be consistent across patients' experiences.

There was a low response rate (n=16) to the question about meeting spiritual needs. A couple of comments suggested that this question may not have been seen as relevant to a number of people, *“This is a hospital not a church”*. Whereas another participant felt differently, acknowledging that they did have spiritual needs and that these were not addressed, *“I think I was left to deal with my spiritual beliefs alone.”*

The survey comments have highlighted the differences in needs for patients affected by cancer, where some acknowledged these needs and others didn't place any importance on particular needs to their own experience. This is consistent with the Supportive Care Model (Fitch, 2008) which illustrates that some will require more support than others and acknowledges that these needs are unique to the individual. Another point to take note of is the tendency found for patients to report high patient satisfaction (which may not reflect true satisfaction) in patient feedback surveys, with standard positively framed questions or statements (Dunsch et al., 2018). This means that any dissatisfaction identified from the

Table 7*Patient Questionnaire Results*

Question	Agree or Somewhat Agree (%)	Somewhat Disagree or Disagree (%)	Total % (Total <i>n</i>)
1. I was involved in my treatment and care decisions.	100 (29)	0.0 (0)	29
2. My family/whanau were able to be involved in my treatment and care decisions as I wished.	100 (26)	0.0 (0)	26
3. Myself and my family/whānau were linked to services when needed which were able to support my cultural and spiritual needs.	95.5 (21)	4.5 (1)	22
4. The place in which I had conversations with health care professionals about my condition, wellbeing or treatment met my needs for privacy .	93.3 (28)	6.7 (2)	30
5. The place in which I had conversations about my condition, wellbeing or treatment met my cultural needs.	94.4 (17)	5.6 (1)	18
6. The place in which I received my treatments met my privacy needs.	92.9 (26)	7.1 (2)	28
7. The people involved in my care had the time to discuss my concerns fully with me and my family/whanau.	92.6 (25)	7.4 (2)	27
8. I found information resources and services relevant (in their content, format and how it was shared) to my cultural needs.	94.4 (17)	5.6 (1)	18
9. My social support needs were considered and addressed throughout my care.	81.5 (22)	18.5 (5)	27
10. My psychological (emotional) needs were considered and addressed throughout my care.	75.9 (22)	24.1 (7)	29
11. I was informed of my rights to be cared for in a manner which is in agreement with my spiritual beliefs.	82.4 (14)	17.6 (3)	17
12. My spiritual needs were considered and addressed throughout my care.	81.2 (13)	18.8 (3)	16
13. I was well informed of the process when I moved from treatment to follow up.	89.3 (25)	10.7 (3)	28
14. My rehabilitative needs were assessed, and I was referred appropriately if needed.	91.7 (22)	8.3 (2)	24
15. I was well informed of the supportive care services available to me.	85.2 (23)	14.8 (4)	27

survey should be taken seriously because patients tend to report more positively than what is reported.

5.2 Qualitative Findings – Patient Interviews

Four key themes were identified across the data from patient interviews and survey comments, which are outlined below.

Theme 1: People will never forget how you made them feel.

Subtheme 1: Positive interactions and feelings.

Subtheme 2: Just another case.

Subtheme 3: Concern for staff.

Theme 2: Lack of privacy.

Theme 3: Role of family/whānau.

Subtheme 1: Foundation of support.

Subtheme 2: Nuances of support.

Theme 4: Unmet communication and information needs across the continuum

Subtheme 1: Not knowing what to ask in the initial consultation.

Subtheme 2: Not knowing fully what to expect.

Subtheme 3: Uncertainty when out of hospital.

5.3 Theme 1: People will never forget how you made them feel

There was a noticeable weight placed on the importance of interactions with staff and how they perceived these interactions, or how these interactions made them feel. This suggests that patients see staff as an important part of their cancer experience. As discussed in chapter two, effective communication and a positive interpersonal relationship with the health professional is of great importance to patients and family members (Mazor et al., 2013). This was evident in the current study where participants often referred to their interactions with staff. Many of the interactions discussed by participants involved the initial consultation where discussions were had about diagnosis and treatment options.

5.3.1 Subtheme 1: Positive Interactions and Feelings

Participants discussed positive communication with the staff they interacted with. Participants felt they had honest and clear communication about their diagnosis and thorough explanations of the treatment options available.

“The original diagnosis came from...I'm guessing he was more registrar than a specialist, he was one of the guys there, but he was very good. Couldn't complain. They're very honest and upfront about what it was and what possible options are ahead as far as making the problem go away.” – Frank.

Although not necessarily directly a response to the questions in the survey or interview questions, how staff made them feel was clearly important to most participants. It's what patients remembered very clearly about their experience. Although there was some discussion about the differences between some staff, there was an overall heart-felt appreciation for the people responsible for their care.

“...with I guess she was a registrar, and a male nurse, both exceptional people. Couldn't fault them. Very, very kind human beings, the pair of them.” – Frank.

“I felt really cared for, respected, and I felt that, yeah, that they were very professional in the way they handled it.” – Laura.

“Dr Claire Hardie is culturally respectful and makes me feel valued.” – Anonymous survey comment.

“I was very impressed with my care during my treatment. I was diagnosed and treated really promptly and all the staff were so empathetic, they were amazing.” – Anonymous survey comment.

“Throughout my treatment I felt very safe the staff were all amazing thank you.” – Anonymous survey comment.

5.3.2 Subtheme 2: Just Another Case

As seen in the previous theme, and consistent with the literature, patients have a need for positive relationships with health care professionals and to feel valued by staff who are empathetic and engaged. This reassures patients that they are treated as a person, and not just another number (Rapport et al., 2019). A few participants discussed their interaction with their specialist which gave the feeling of a lack of acknowledgment, or time given for how serious it was for the patient.

“...because they've done it 2000 times or 10,000 times. It just becomes another operation. But for you, it's your first time and you don't understand what's really going to happen to you.” - James.

"...and I didn't actually spend a lot of time with the surgeon on that day. He was running a little bit late, and he just popped into the consulting room, and said, "Oh, we've found some tumors, and you've got an aggressive type of cancer." - William

"The surgeon told me that 'if it's spread, it's the same now as it is next week, it won't make any difference'. It did make a difference to me, as it is my life that is being talked about." – Anonymous survey comment.

Patients with a cancer diagnosis are confronted with life and death and have likely not been in this situation before. The comments suggest that for these participants, their specialist's delivery of news or response to their concern, did not reflect the magnitude of the impact felt by these patients.

One interview participant, Mere, had a particularly poor experience with the delivery of her diagnosis and follow up care after this. *"Was given the diagnosis in a dark room with six other beds by two doctors. They gave the diagnosis and left the room."* Mere described being given this news without a support person with her and no opportunity to ask questions. She explained how she *"broke down"* as she was left to deal with this news on her own while in a shared hospital room. Mere went on to have a negative interaction post-treatment with a nurse who was *"rough and rude"*, *"Felt like she didn't care."*

5.3.3 Subtheme 3: Concern for Staff

There was also a noticeable and genuine concern for staff members, particularly for nurses and their workload. Despite Mere's negative interactions with some staff members, she still expressed this genuine concern for the nurses around her. She explained that *"they're trying to do everything"*. She also discussed on more than one occasion where she came

across nurses who were visibly upset, and she ended up supporting them. This concern for staff was shared by other participants.

“Well, I guess the conversation needs to be had around the nurses who are in the ward, male and female, but no distinction there’s some, I don’t care what - there’s some exceptional human beings amongst some of those people. But they have to work way too hard, to the point that I felt guilty about ringing the buzzer because I needed a hand with something. I know they’re too busy, because they’re running around trying to get stuff done, they’re lucky if they can grab a sandwich somewhere, but some exceptional kind, caring human beings amongst some of those people.” - Frank

This genuine concern for staff is consistent with the theme of *constraints*, subtheme – *important, but not practical* identified in the staff comments, where staff frequently reported a lack of time, not having enough staff and having a heavy workload. These two sub-themes suggest that the identified constraints may be impacting staff negatively, and also affecting the quality of care for patients, where for example, a patient has not wanted to ask for help.

5.4 Theme 2: Lack of Privacy

Most survey participants agreed that the place where they had conversations met their privacy needs. Although a lack of privacy was not a concern for many according to the patient survey results, it seemed important to the experience of the patients who did discuss it in both the survey comments and interviews. Most discussed a lack of privacy with shared rooms, which was also reported as a concern by staff.

“It’s hard to have a private conversation when you are in a ward with four other patients.” – Anonymous survey comment.

“The only time I felt a bit vulnerable was on the day I was discharged from the hospital, and that's the day they took the catheter out and they were taking other stuff out as well the day before that. When the surgeon's assistant came up to me, and he said to me, and it's not very private unfortunately in the hospital ward. The only privacy you get is by having the curtains around you, but everyone else in the room, which there were three other people in there, they could hear what was going on.” – William

William went on to discuss a conversation he had with his surgeon where he felt uncomfortable with his lack of privacy.

“He mentioned that the prostate was in a pretty bad way, but he did say to me, in quite a reasonably loud voice, he said that one of the cuts that they made was very close to where one of the tumours was, and he said that there could be some issues later on, and they would be looking at radiation, stuff like that... I didn't really like other people hearing that, though. But that's the way it was. It wasn't very private.” – William.

William acknowledges that he didn't like the lack of privacy and seems to accept that that's just the way it is.

A lack of privacy wasn't just experienced by patients staying in shared rooms. One survey participant reported hearing details of other patients' cases while waiting for her appointment.

“The consulting rooms appear to be a number of rooms which all open to a central office. When sitting waiting for my turn with the consultant - I could hear what was

going on in the office, to the point of hearing the surgeon dictating patient notes, including names and diagnosis.”

This ties into the theme of space and place, identified in the staff survey and comments, not meeting the needs of patients and staff, with limited private spaces available, and ‘thin walls’ for example.

One interview participant provided a different perspective to privacy concerns. Shaun discussed the lack of privacy during his initial conversation with the nurse just prior to having chemotherapy, and during treatment. He acknowledged the lack of privacy and how it could be a concern for others. However, he viewed his own perspective as positive, being around other people in the same situation.

“We're all in the same boat, in my opinion. I can certainly see why some people might be upset at that, because it's not really confidential, you can hear what other people are... But saying that, if you're on a drip, you're getting chemo, you're not really paying much attention. To be honest with you, we're in a room, there's 10 of you doing the chemo, whatever process, I didn't mind that and I think I'd be happier in that process than by a private room. And that sounds really strange, but to me it was like, you see other people in the same situation as you are.” – Shaun.

5.5 Theme 3: Role of Family/Whānau.

5.5.1 Subtheme 1: Foundation of Support

The role of family/whānau in the experience of patients with cancer was discussed across most of the interviews. Family/whānau are an important coping strategy for cancer and for some, are considered the foundation to their experience (Egan et al., 2016). It became evident how important it was to have family/whānau present at appointments for their role in

helping to remember what was said, what to ask, and to help understand information. This is especially important at a time when patients may find it difficult to take in new information after being given a diagnosis (Lobb et al., 2011).

“The support, guidance and advice of my daughter was integral to my understanding of the process and treatment options.” – Anonymous survey comment.

“I think that's why my partner is going to come to my next appointment, because it's like... My mum always says to me, "Did you ask..." – Shaun.

“...so my listening skills I thought were pretty good but I was listening for the things I wanted to hear, and they listened to other sorts of things so that's something positive taking your family with you...” – Kaha.

James discussed feeling good about going into an appointment and therefore decided not to take any family/whānau members with him. His quote highlights the importance of having family/whānau support with patients at appointments to help cope with the exchange of information at a time where some may find it difficult to take in any information and when *“a lot of key information is required to be given” – Staff member.*

“Yeah, this is what we're going to do. This is what's going to happen.” Okay. And of course I'm in shock. I've got no support person. I don't know what questions to ask because I'm not even thinking about what questions to ask because I'm just blown away by it” – James.

5.5.2 Subtheme 2: Nuances of Support

Although Kaha described the importance of having family/whānau with him at these appointments above, especially coming from a “whānau centric”, “collective culture”, he also

discussed the impact that it had on his willingness to ask more intimate questions. Kaha explained not fully understanding the implications of his surgery and had felt “too whakamā” (embarrassed) to ask intimate questions in front of his family/whānau. The following are long quotes, but they capture the essence of Kaha’s struggle to meet his own need while also not wanting to feel like he is letting his family/whānau down.

“Yeah I think they were but I think I was too probably whakamā, too what do you call it, too embarrassed to sort of ask, and my wife didn't ask because she said whatever it is Kaha we'll manage it, and you know my kids didn't ask because they thought oh that's dad's business, and I didn't ask coz they were there and I didn't want to go into details of those kinds of things, and I just wonder whether, for us, we do things collectively but I wonder that given what I was going through is so intimate and personal, whether it should be that way all the time.”

Kaha goes on to explain the subtle difference in how staff may have been able to meet his need for more information.

Possibly, if I was given the option if one of the doctors said to me 'Kaha, so that's all Kaha, and now can I suggest that just you and I just have a talk for a couple of minutes', I probably would have taken it up, if the doctor or the nurse if they had said 'Kaha do you want to talk to us privately for a couple of minutes' in front of my family I would have said no, so if they'd given me the option in front of my family I wouldn't have put my family down I would have said 'no no, what you want to say to me my family can hear' but if they said 'Kaha, would it be ok for me to talk to you for a couple of minutes alone' then I probably would have opened up a little bit more so - I would have felt more - yeah I probably would have felt more comfortable in certain aspects...”

5.6 Theme 4: The Importance of Communication and Information Needs Across the Continuum

Some participants expressed uncertainty and not knowing right across the continuum, which was also meaningful because of how it impacted patients. The unmet need for communication and information created a lack of clarity, which led to a sense of concern and distress for some participants. The importance of communication and the need for information to help prevent or ease any distress is shown through the examples that follow.

Kaha had his family/whānau with him at his appointments which as discussed previously, helped to meet some of his needs for information. However, this also meant that Kaha felt too whakamā to discuss the more intimate concerns he had related to his diagnosis and its treatment. So, although he felt that he had clear communication from his specialist about the procedure and understood there would be post-operation implications, he felt he did not fully appreciate the side effects and its impact on his quality of life.

“...so I think that's the big thing for me is I didn't really understand as much as I should have, I thought that I was going to be functional with some support help or drugs - um so the personal things were the things that I found most difficult to explore.”

The importance of communication and information about certain needs was also evident post-treatment when Kaha was still living with the side effects of his treatment.

“and post the operation I went back there 6 or so months later and they said to me have you tried any of those things and I said nah, and um I think if they had said look we're going to prescribe you something they'd been a little more proactive I would have been less inclined to accept the then and there situation and that's still the case”.

These findings suggest the need for health care professionals to initiate conversations around how to address the more intimate concerns of patients. It is an area that some patients find embarrassing to talk about (O'Brien, 2011), and is a topic sometimes not addressed by clinicians "men reported that the sexual and emotional consequences of treatment were not routinely discussed unless they initiated the topic themselves." (Speer et al., 2017, p 20).

As discussed above, under the role of family, James described an appointment with his specialist where he received the results of some tests and was given bad news. He explained being in a state where he didn't know what to ask. This meant that James went home without the information he needed, as it was not until he got home and had time to "settle down" that he was able to think of all the things he needed to know. But as James explained, it was too late. *"...how could I possibly ask the correct questions in that state and when I settled down at home it is too late because you can't talk to your surgeon till your next appointment because he is so busy so you suffer for two to three weeks not knowing the answer to your new questions till then."* – James.

There was also a sense of uncertainty or distress for some patients who were in between appointments, had completed treatment, or were waiting to hear about test results or next steps.

"After the initial diagnosis there was around 3 weeks where there was no emotional support. Communication from medical staff at this time was non existstant [sic] no telephone contact to enable me to make contact because doctor had not contacted me as promised." – Anonymous survey comment.

"it was quite dark days there for a while until we knew what was going on, especially with regarding the scans, and also the bone scan as well, because we had to wait

about a week to get those ... or a couple of weeks by the time we got both of them, so they were quite dark days.” – William.

“But no, that's the kind of... I guess, maybe the communication, once you're out of their care, is less. I always felt like I was communicated with when I was in, but once you finished your treatment, you're outside it, maybe then it's just... You come in, when you're there they treat you really well. But there's not a lot of communication... Yeah, I was very clear about what the theme was going to be, going forward. That's probably what frustrates me a bit more, is that I don't know what the plan is now.” – Shaun.

Some patients discussed having access to a number to call for any concerns they had post-treatment. Being able to contact a nurse while back at home was seen as helpful to participants but did not always work out. This example shows how the unmet need for communication or information needed at the time, meant that for Shaun, he ignored his own symptoms and even took the wrong medication.

“So when I started throwing up and vomiting et cetera, I did ring that number and no one answered...It literally rang for about 18, 19 times, so I think it just went to the ward. So I just ignored it. And there was another time where, I can't remember, I was sick again so I took the medication, I actually took the wrong medication.”

Having no-one available to answer the phone is an example of how the constraints reported by staff such as busy workload and not enough staff, may be impacting on patients' needs.

Chapter 6: General Discussion

6.1 Study Aims

This study aimed to find out how well MDHB services are meeting the supportive care needs of their patients. It sought to explore how confident and supported staff felt in meeting the supportive care needs of patients, and how well patients thought their supportive care needs were identified and addressed. Surveys were utilised for both groups and were designed to assess the degree in which participants felt the supportive care needs of patients identified in the Framework were being met. Semi-structured individual interviews with patients were also carried out to gain further insights into the supportive care needs of patients and to identify any unmet needs.

6.2 General Discussion

Overall, most staff agreed or somewhat agreed with the statements in the survey, reporting high agreement with understanding the psychological and social needs of patients, and with there being a culture of whānau inclusion. There was lower agreement though with staff feeling that the environment met the needs of patients and with feeling supported by MDHB to reflect on situations of difficult communication. One major theme, *constraints* was identified through the thematic analysis of comments in the staff survey, and three sub-themes; *limits of space and place*; *important, but not practical*; and *working within constraints*. Staff consistently expressed the limits of the spaces and places in which they worked. Approximately one third of staff thought that the environment they worked in did not meet the privacy or cultural needs of their patients and family/whānau. A lack of available private spaces for conversations meant that staff were having discussions on the move, in public spaces. One staff member noted how they thought patients may not give

honest answers to how they were feeling because they might feel exposed when talking in public places. This could create a missed opportunity to identify any needs. Staff often expressed this notion of acknowledging the importance of meeting the needs of patients but at the same time identified why it was difficult to do so. Staff consistently reported a lack of time, heavy workload, and not enough staff, which impacted on the way in which staff worked, for example running late to try and meet the needs of patients with more complex needs.

The findings suggest a sentiment that some staff feel the needs of patients outside of their physical treatment care are important, but not necessarily realistic in the current environment. There is a sense of ‘one or the other’, and with these constraints, the physical and treatment-related needs are priority, and the supportive care needs perhaps a ‘nice to have’.

Patients expressed a genuine concern for staff, and the pressure they were under. Concern for staff was a sub-theme identified from the patient data. Patients described how busy nurses were and felt that nurses were trying to do everything. Patients gave examples of how it impacted them, such as feeling guilty about pressing the buzzer. One participant described finding more than one nurse visibly upset, and she ended up supporting them. This suggests that the heavy workload, lack of staff and lack of time described by staff is not only affecting staff but impacting on and being felt by patients. Patients are taking on the role of carer, or not feeling like they can ask for help.

Interestingly, findings from this current study are similar to two of the key findings in a review (Carietri et al., 2018) of the barriers to the implementation of supportive care in cancer: *Lack of adequate resources and infrastructures* and *Professional burn-out of cancer clinicians*. These barriers capture the elements of both themes/subthemes identified and

discussed in this current study, *constraints*, and *concern for staff*. Supportive care in cancer requires a multi-disciplinary approach which can require more time and effort. Carrieri et al. (2018) acknowledge that most healthcare services worldwide are under-funded and experience extreme pressure trying to work with limited resources. The authors also point out that some healthcare workers may therefore see supportive care as more of a burden, another important but unachievable task to add to their already heavy workload.

Health care professionals are essential to the delivery of health care, to meet both the physical treatment and supportive care needs of patients. Trying to work with heavy workloads and low staffing levels alongside increasingly complex care, creates a working environment that can make it difficult to provide quality care and can contribute to health professional burnout (Humphries et al., 2013). The findings of this current study suggest that staff are working with a number of constraints, with the physical environment they work in, heavy workload, lack of staff and limited time, which all affect how they are working day-to-day. And while meeting the supportive care needs of patients is seen as important, it seems unattainable at this time. Despite this, staff still expressed a desire to do more and learn more to meet the supportive care needs of patients, for example learning more about identifying the psychosocial needs of patients and giving examples of how they would like to make the spaces feel less clinical.

Overall, the quantitative data from the patient survey showed that participants perceived their supportive care needs to be well met, with high levels of agreement across most questions. For example, every participant felt that they, and their family/whānau were able to be involved in their treatment and care decisions. Patients had lower levels of agreement with how well they felt that their psychological, social and spiritual needs were considered and addressed. There were some mixed responses in the comment sections to psycho-social-

spiritual needs where some patients described not discussing any support beyond being given a pamphlet, while others went on to have psychological counselling. Most staff felt that they had sufficient understanding of the psychological and social needs of their patients, however, were considerably less confident in utilising evidence-based tools to identify or clarify these needs with patients, particularly social needs. Some staff reported using screening tools while others did not know of any, hadn't had any training in this area or knew that there were screening forms available but hadn't used them.

Some MDHB clinicians may have their own systems in place to identify needs, but these findings suggest an ad hoc approach, with no organisation-wide systematic process in place to identify and address the supportive care needs of patients and their family/whānau. This is consistent with other findings (Schouten et al., 2018) that looked into the barriers to the provision of supportive care in cancer, where only a small minority of health care professionals used a systematic approach to identify and address psychosocial concerns.

When interpretations of the findings related to Māori were discussed with a Māori senior clinical psychologist, the lack of protocol, process or tikanga was discussed. The way in which Mere received news of her diagnosis and treatment, was handled in a way which caused significant distress. Had there been certain processes in place or tikanga/protocols followed, this may have reduced the level of distress experienced. For example, checking to see if there was a support person available, establishing some kind of rapport or empathy before delivering the news. Mere went on to be referred to and utilised Māori, social and spiritual support services, which she found valuable. Identifying the need for these services earlier by the use of structured processes may have been helpful to Mere's experience.

Staff play a crucial role in addressing the supportive care needs of patients. When needs are identified in a timely manner and patients are referred to the required services, this

can help to reduce the symptom burden (for example depression and anxiety) associated with cancer and its treatment and improve their quality of life (Bultz et al., 2013; Carlson et al., 2012; Wagland et al., 2016).

Further highlighting the important role of staff is the major theme identified in the patient data, *People will never forget how you made them feel*. Patients reported positive interactions with their clinicians and frequently expressed appreciation for the staff responsible for their care, describing feeling safe and valued. Some patients however experienced feeling less valued or important in their interactions with their specialist and implied feeling like *just another case*. Patients value caring clinicians, and a positive interpersonal relationship is of fundamental importance to patients and their family/whānau (Mazor et al., 2013).

These findings suggest that patients perhaps view staff or health care practitioners as part of their support team in this battle against cancer and therefore have some expectations around feeling like they are not just another number to them. When patients do feel like *just another case*, perhaps they feel like their specialist won't try their hardest to help them win their battle against cancer. This relationship appears to go both ways, where patients expressed genuine concern and gratitude for the people caring for them and the pressure staff were under.

The *role of family/whānau* was a major theme identified in the interviews. Family/whānau were viewed as essential to their experience, and played an important role providing mainly practical support. This included helping to remember what was said by clinicians or help with remembering what questions to ask. Studies consistently show how family/whānau play an important role for patients affected by cancer providing essential practical and emotional support. A few comments by participants in the survey pointed out

that they did not have any family around to attend appointments with them or to help them make decisions. This group of patients could be at higher risk of unmet needs not having any family/whānau available to support them.

This study used a structured framework to design the survey but also utilised semi-structured interviews with patients which allowed for greater depth of data and for ideas that were important to patients to be captured. Of interest is the differences in information collected from the quantitative and qualitative responses. The quantitative data captured in the patient survey was more positive than the qualitative findings, which identified some unmet needs that were important to patients. Utilising both methods in this study meant that further insights and context to the areas explored in the survey questions could be captured that otherwise would have been missed. The need for communication and information regarding patients' diagnosis, results or treatment related side effects was a theme identified through the qualitative responses and interviews. When this need for timely communication and information was not met, the qualitative data was able to elaborate on what this meant for the patients and describe how it caused uncertainty and some distress for patients.

6.3 Suggestions/Recommendations

The findings from this current study suggest there may not be a systematic approach to identifying and meeting supportive care needs at MDHB, Palmerston North Hospital. Having separate systems for different needs may be time consuming and confusing. A systematic and integrated approach to supportive care could address many of the issues discussed above. Agreement on one simple, but holistic and structured screening tool that staff felt confident using may be helpful to identify patients who require further support. A screening tool that covers psycho-social-spiritual-cultural needs of patients may also take the pressure off staff if they didn't want to make any assumptions about what needs a patient might have. This was

mentioned in the staff comments, not wanting to assume that patients have certain needs, such as requiring cultural support. Re-evaluating needs by using the same screening tool more than once across the cancer trajectory could also help to identify if any earlier needs had been met or not, or if there were any new needs for support (NCCN, 2021).

This study also highlighted that patients have different needs. Some found certain areas important to their experience, some viewed the wider supportive care needs as valuable but not personally needed, while other comments suggested that they thought the hospital's role is to meet the physical treatment needs. This further supports the need for tailored approaches to suit individual needs.

Clinical audit is part of an ongoing process, where changes are implemented and re-audited. Regular feedback from current and future patients about their experience may be useful to gather ongoing insights from a larger group of patients and to monitor any changes to patients' experiences. Continuing to collect feedback will help add to these findings. For example, patients could be provided with a paper survey, link or QR (Quick Response) code in the waiting room for a short survey that asks about their service experience. This could be available for a period of time every six months for example. Of the 399 possible patient participants in this study, 153 people did not have a recorded email address. Having the details of the survey in the waiting room could help mitigate this in future, if there are no updates to the contact details of patients.

What comes from these findings will need to take into consideration the constraints that were highlighted in this research. Where rising levels of burnout in health care professionals are a serious concern (Reith, 2018), asking more of staff who already have a heavy workload, lack of time and limited staff numbers would not be conducive to better patient outcomes or to the wellbeing of staff. Having a systematic approach with protocols or

procedures in place for timely screening, and for when and how to refer to psychological, social, spiritual and cultural services may save time and resources by avoiding more complex needs later on.

6.4 Study Limitations

There are a number of limitations to this study. Firstly, there was a low response rate to both staff and patient surveys, making it difficult to make any generalisations. Continuing to collect further feedback as discussed above from current and future service users will help add to these findings.

Although some rich data was collected through the patient interviews and comments, it was mainly from those who had experienced surgery or chemotherapy, and not so much radiotherapy. Experiences related to this service were lacking. There were also no survey patient participants aged between 18 and 35. Younger patients have been found to report lower levels of patient satisfaction compared with older patients and have also been found to have higher unmet needs.

6.5 Future Research

Cancer is a complex disease, with different diagnoses and treatments. As well as different demographic factors, there are also different stages which require different needs. Future research into specific groups of patients could help to identify common met and unmet needs of cancer survivors specific to the stage of their journey. For example, this study found uncertainty for those post-treatment particularly with communication and information needs. Focussing on patients in this part of the continuum could help to explore the needs and unmet needs of this group in more detail and with a larger number of people.

If family/whānau members are helping to meet practical needs around information and communication for patients, those without family/whānau could be an area of interest to learn more about how they cope or manage the impact of cancer and treatment. Finding a way to access younger patients to explore the perspectives of this age group could give some wider insights into needs that may not have been reported by older patients in this study. What may also be interesting, is to look into the prevalence of concern for staff or how often patients feel the need to support staff.

6.6 Concluding Comments

There is no shortage of research into the supportive care needs of those affected by cancer. The integration of supportive care into routine oncology services is widely encouraged and valued. However, studies on the unmet needs of patients suggest that this might not be happening. The patient survey found that overall, patients felt their supportive care needs were mostly well met throughout their experience with the cancer services at MDHB, Palmerston North Hospital. There was very high agreement by patients feeling like they and their family/whānau were involved in their treatment and care decision making process. In the qualitative data, patients reported feeling safe and valued. The findings do however suggest that some needs may not be being met across the cancer continuum.

There is less research into healthcare workers' perspectives of meeting the supportive care needs of patients. This study provides some insight into staff's perception of the barriers to the provision of supportive care for patients. A number of barriers were identified and discussed which were directly felt and experienced by the patients.

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Appendix A: Staff Participant Information Sheet



A review of MidCentral District Health Board's Cancer Services performance against 'He Anga Whakaahuru' - The Supportive Care Framework.

PARTICIPANT INFORMATION SHEET – STAFF QUESTIONNAIRE



Kia ora and thank you for your interest in this study. My name is Renee Vitale and I am a student at Massey University carrying out this research for a Master of Science in Psychology. My supervisor is Dr Don Baken, Research Consultant and Senior Clinical Psychologist, Massey University.

I would like to invite you to take part in this research, looking at how well MidCentral DHB Cancer Services are meeting the supportive care needs of their patients. We are interested in everyone's thoughts, not just those for whom supportive care is a focus. We are looking at staff training and your confidence in your skills, whether you feel supported to do this work and whether there are appropriate spaces for conversations with patients.

This information sheet provides you with details about what the study is about, why it is being done and what to expect, so please read carefully before deciding if you would like to participate or not. If you decide to participate, I thank you for sharing your thoughts.

What is the purpose of this study?

Palmerston North Hospital want to know how well they are meeting the social, emotional, cultural and spiritual needs of their cancer patients. They are wanting to hear from staff and recent patients of their cancer services. Palmerston North Hospital are looking to improve their services and your feedback will help to identify what is working well, and what changes may need to be made.

This study will assess Palmerston North Hospital's performance against some recommendations (He Anga Whakaahuru – The Supportive Care Framework) on how supportive care services should be provided to cancer patients and their families/whānau.

What will happen if I take part?

You will be asked to complete an online anonymous questionnaire through Survey Monkey. The questionnaire should take about 5 minutes.

What are my rights?

You are under no obligation to accept this invitation. If you decide to participate, you have the right to:

- ☐ *decline to answer any particular question;*
- ☐ *withdraw from the study; (Please note, as the survey is anonymous, you will not be able to withdraw after you press submit)*

- ☐ ask any questions about the study at any time during participation.

What are the possible benefits and risks?

There are no expected significant risks with completing this questionnaire. It is our hope that this project will benefit patients and staff in the future as MidCentral DHB seek to improve their services.

What happens with my information?

All survey information will be anonymous and be kept confidential. Only myself and my supervisor will see the survey responses. Participants will be given an alias when sharing quotes from comment sections. The findings of this research will be shared with MidCentral DHB Cancer Services management and staff, and may be presented at a conference or in a peer reviewed journal. Although demographic data will be collected, the only information provided to MidCentral DHB will be summarised information from the questionnaires and anonymous comments.

Project contacts:

Renee Vitale – Master's Student: Renee.Vitale.1@uni.massey.ac.nz

Dr Don Baken – Supervisor: D.M.Baken@massey.ac.nz

Cultural Support

We respect the importance of cultural beliefs and values in research settings and should you require support outside of your own networks then you may wish to contact the Pae Ora Māori Health Service at Palmerston North Hospital for assistance.

Phone: (06) 350 8210

Email: maorihealthunit@midcentraldhb.govt.nz

Ngā Mihi Nui

Renee Vitale

This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern A, Application 20/23. If you have any concerns about the conduct of this research, please contact Dr Negar Partow, Chair, Massey University Human Ethics Committee: Southern A, telephone 04 801 5799 x 63363, email humanethicsoutha@massey.ac.nz.

Appendix B: Staff Questionnaire



STAFF QUESTIONNAIRE

1. What area of cancer screening, treatment and support do you work in?

Screening ☐ Treatment ☐ Support ☐

2. What is your gender?

3. What is your age?

18-24 ☐ 25-34 ☐ 35-44 ☐ 45-54 ☐
55-64 ☐ 65-74 ☐ 75+ ☐

4. What ethnic group do you belong to? (select as many as applicable).

New Zealand European ☐ Māori ☐ Samoan ☐ Cook Island Māori ☐ Tongan ☐

Niuean ☐ Chinese ☐ Indian ☐ Other (Such as Dutch, Japanese, Tokelauan).

Please state:

5. What is your role?

Admin ☐ Receptionist ☐ Doctor ☐ Nurse ☐ Allied Health ☐

Other ☐ Please state:

Please read the statements below and choose the answer that best describes how much you agree with the statement. There is space for any comments you may wish to make at the end.

Statement	Agree	Somewhat agree	Somewhat disagree	Disagree
6. The environment in which I interact with patients meets their privacy needs.				
7. The environment in which I interact with patients meets their cultural needs.				
8. When I interact with a patient, and their whanau we have enough time scheduled to discuss what is important to them.				

9. I have the required experience and skills to handle difficult conversations (such as giving bad news).				
10. I am supported by MidCentral Health to reflect on situations of difficult communication.				
11. I know how to use / access interpreter services if required.				
12. I have sufficient understanding of the impact of social needs on my patients and their whanau.				
13. I know how to use evidence-based tools or screening methods to assist in identifying and clarifying social needs of my patients.				
14. I have sufficient understanding of the psychological impact of cancer on my patients and their whanau.				
15. I know how to use evidence-based tools or screening methods to assist in identifying and clarifying psychological needs of my patients.				
16. There is a culture of whanau inclusion in services provided to our patients.				
17. Systems are in place to ensure patients and their whanau are fully informed of their right to be cared for in a manner which is in agreement with their spiritual beliefs.				

Please add any further comments about the questions above in the box below.

Thank you for taking the time to fill out this questionnaire. If you have any questions or concerns that have been raised as a result of this questionnaire, please contact:

Renee Vitale – Master’s Student: Renee.Vitale.1@uni.massey.ac.nz

Dr Don Baken – Supervisor: D.M.Baken@massey.ac.nz

Appendix C: He Anga Whakaahuru – Supportive Care Framework. Staff-related standards

Staff-related standards	
1.10	The physical environment enables conversations and therapeutic interventions to be undertaken in a manner that meets the privacy and cultural needs of people affected by cancer.
2.1	Within service delivery, appropriate time is scheduled to allow for full discussion, with the patient and their whānau about what matters to them.
2.3	Healthcare workers involved in difficult conversations, for example “breaking bad news”, have the required experience and skills.
2.4	Organisations have services in place to support health workers to reflect on situations of difficult communications (for example supervision, case review).
2.5	Interpreter services are available and health and support workers are skilled in their use.
4.2	All health and supportive care workers participate in education and training programmes to increase their awareness and understanding of the impact of social needs on the person affected by cancer and their whānau.
4.5	Health and supportive care workers proactively use evidence based tools or screening methods to assist in identifying and clarifying social needs from a holistic perspective.
5.2	All workers participate in education and training programs to increase their awareness and understanding of the psychological impact on the person affected by cancer and their whānau.
7.1	A culture of whānau inclusion in decision making is embedded in all services and organisations that provide supportive care to people affected by cancer.
8.2	Systems are in place to ensure people affected by cancer and their whānau are fully informed of their right to be cared for in a manner which is in agreement with their spiritual beliefs.

Appendix D: Patient Information Sheet – Questionnaire



A review of MidCentral District Health Board's Cancer Services' performance against 'He Anga Whakaahuru' - The Supportive Care Framework.

PARTICIPANT INFORMATION SHEET – QUESTIONNAIRE



Kia ora and thank you for your interest in this study. My name is Renee Vitale and I am a student at Massey University carrying out this research for a Master of Science in Psychology. My supervisor is Dr Don Baken, Research Consultant and Senior Clinical Psychologist, Massey University.

I would like to invite you to take part in this research, looking at how well MidCentral DHB Cancer Services are meeting the supportive care needs of their patients.

This information sheet provides you with details about what the study is about, why it is being done and what to expect, so please read carefully before deciding if you would like to participate or not. If you decide to participate, I thank you for sharing your thoughts.

What is the purpose of this study?

Supportive care is about improving the quality of life for those with cancer, their family and whānau. MidCentral DHB, Palmerston North Hospital want to know how well they are meeting the social, emotional, cultural and spiritual needs of their cancer patients. They are wanting to hear from current and recent patients of their cancer services. Palmerston North Hospital are looking to improve their services and your feedback will help to identify what they are doing well, and what changes may need to be made.

This study will assess Palmerston North Hospital's performance against some recommendations (He Anga Whakaahuru – The Supportive Care Framework) on how supportive care services should be provided to cancer patients and their families/whānau.

What will happen if I take part?

You will be asked to complete an anonymous online questionnaire, which will take about 10 minutes. You will also be given the opportunity to request a summary of the research and indicate if you would be open to sharing more of your experiences through an interview with myself.

What are my rights?

You are under no obligation to accept this invitation. If you decide to participate, you have the right to:

- ☐ *decline to answer any particular question;*
- ☐ *withdraw from the study; (Please note, as the survey is anonymous, you will not be able to withdraw after you press submit)*

- *ask any questions about the study at any time during participation;*
- *be given access to a summary of the project findings when it is concluded if you request it.*

What are the possible benefits and risks?

There are no expected significant risks with completing this questionnaire, your treatment will not change or differ if you participate in this research or not. It is our hope that this project will benefit patients in the future as MidCentral DHB seek to improve their services.

What happens with my information?

All survey information will be anonymous and be kept confidential. Only myself and my supervisor will see the survey responses. Participants will be given an alias when sharing quotes from comment sections. The Summarised findings of this research will be shared with MidCentral DHB Cancer Services management and staff, and may be presented at a conference or in a peer reviewed journal.

Support:

If completing this questionnaire causes you any discomfort and you feel you need some support, please contact the Cancer Society supportive care team: phone - (06) 356 5355.

We respect the importance of cultural beliefs and values in research settings and should you require support outside of your own networks then you may wish to contact the Pae Ora Māori Health Service at Palmerston North Hospital for assistance.

Phone: (06) 350 8210

Email: maorihealthunit@midcentraldhb.govt.nz

Project Contacts:

Renee Vitale – Master's Student: Renee.Vitale.1@uni.massey.ac.nz

Dr Don Baken – Supervisor: D.M.Baken@massey.ac.nz

Ngā Mihi Nui

Renee Vitale

This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern A, Application 20/23. If you have any concerns about the conduct of this research, please contact Dr Negar Partow, Chair, Massey University Human Ethics Committee: Southern A, telephone 04 801 5799 x 63363, email humanethicsoutha@massey.ac.nz.

Appendix E: Patient Questionnaire



A Review of Palmerston North Hospital's Performance against 'He Anga Whakaahuru – Supportive Care Framework.'

PATIENT QUESTIONNAIRE:

A bit about you:

1. What is your gender?

2. What is your age?

18-24 ☐ 25-34 ☐ 35-44 ☐ 45-54 ☐

55-64 ☐ 65-74 ☐ 75+ ☐

3. What ethnic group do you belong to? (select as many as applicable).

New Zealand European ☐ Māori ☐ Samoan ☐ Cook Island Māori ☐

Tongan ☐ Niuean ☐ Chinese ☐ Indian ☐

Other (Such as Dutch, Japanese, Tokelauan). Please state:

4. How were you diagnosed?

Screening ☐ General Practitioner ☐ Emergency Department ☐

Other ☐ Please state:

5. What areas of MidCentral DHB's Cancer detection and treatment services have you experienced? (please select all you have experienced).

Radiation ☐ Surgery ☐ Chemotherapy ☐ Palliative care ☐

6. Cancer type (please select all you have experienced).

Lung ☐ Bowel ☐ Breast ☐ Prostate ☐ Uterine/Ovary/Cervix ☐

Other:

7. Where were you treated?

Inpatient ☐ Outpatient ☐

How was your experience? Please read the statements below and tick which box best describes how much you agree with the statement. There is space below for any comments you wish to make.

Statement	Agree	Somewhat agree	Somewhat disagree	Disagree
8. I was involved in my treatment and care decisions.				
9. My family/whānau were able to be involved in my treatment and care decisions as I wished.				
10. Myself and my family/whānau were linked to services when needed which were able to support my cultural and spiritual needs.				
11. The place in which I had conversations with health care professionals about my condition, wellbeing or treatment met my needs for privacy .				
12. The place in which I had conversations about my condition, wellbeing or treatment met my cultural needs.				
13. The place in which I received my treatments met my privacy needs.				
14. The people involved in my care had the time to discuss my concerns fully with me and my family/whānau.				

How was your experience? Please read the statements below and tick which box best describes how much you agree with the statement. There is space below for any comments you wish to make.

Statement	Agree	Somewhat agree	Somewhat disagree	Disagree
15. I found information resources and services relevant (in their content, format and how it was shared) to my cultural needs.				
16. My social support needs were considered and addressed throughout my care.				
17. My psychological (emotional) needs were considered and addressed throughout my care.				
18. I was informed of my rights to be cared for in a manner which is in agreement with my spiritual beliefs.				
19. My spiritual needs were considered and addressed throughout my care.				
20. I was well informed of the process when I moved from treatment to follow up.				
21. My rehabilitative needs were assessed, and I was referred appropriately if needed.				
22. I was well informed of the supportive care services available to me.				

Please add any further comments about the questions above if you would like in the box below.

Thank you for taking the time to fill out this questionnaire. If you have any questions or concerns that have been raised as a result of this questionnaire, please contact:

Renee Vitale – Master's Student: Renee.Vitale.1@uni.massey.ac.nz
Dr Don Baken – Supervisor: D.M.Baken@massey.ac.nz

Appendix F: He Anga Whakaahuru – Supportive Care Framework. Patient-related standards

Patient-related standards	
1.7	People affected by cancer and their whānau are proactively linked to services which are able to support their cultural and spiritual needs, including Māori and Pacific health providers.
1.8	The person affected by cancer and their whānau are involved with treatment and care planning by all agencies.
1.10	The physical environment enables conversations and therapeutic interventions to be undertaken in a manner that meets the privacy and cultural needs of people affected by cancer.
2.1	Within service delivery, appropriate time is scheduled to allow for full discussion, with the patient and their whānau about what matters to them
3.2	Information resources are relevant (in their content, format and dissemination channels) to the needs of Māori, Pacific and culturally and linguistically diverse groups.
4.1	The social support needs of people affected by cancer is proactively considered and addressed continuously throughout their care
4.3	An integrated and coordinated system of continued social support provides timely, accessible services that meet the needs of the full range of populations
5.1	The psychological wellbeing of people affected by cancer is proactively considered and addressed continuously throughout their care
7.1	A culture of whānau inclusion in decision making is embedded in all services and organisations that provide supportive care to people affected by cancer.
8.1	The spiritual needs of people affected by cancer is proactively considered and addressed along the journey or at each intervention point
8.2	Systems are in place to ensure people affected by cancer and their whānau are fully informed of their right to be cared for in a manner which is in agreement with their spiritual beliefs.
9.1	People affected by cancer moving from intervention into follow-up have a planned approach to their continued medical and supportive care needs which is clearly documented, reviewed regularly and understood by the person and their whānau

Appendix G: Patient Information Sheet - Interview



A review of MidCentral District Health Board's Cancer Service performance against 'He Anga Whakaahuru' - The Supportive Care Framework.

PARTICIPANT INFORMATION SHEET – INTERVIEW



Kia ora and thank you for considering sharing your experiences with MidCentral DHB cancer services. My name is Renee Vitale and I am a student at Massey University carrying out this research for a Master of Science in Psychology. My supervisor is Dr Don Baken, Research Consultant and Senior Clinical Psychologist, Massey University.

This information sheet contains details about why we are doing interviews, what is involved, what the benefits and risks might be, and what your rights are. Please read carefully before deciding if you would like to participate or not. You may want to talk with other people, such as family/whānau friends, or healthcare providers about this. Please feel free to do this. You are more than welcome to have a whānau member or support person with you during your interview.

What is the purpose of this study?

Palmerston North Hospital want to know how well they are meeting the social, emotional, cultural and spiritual needs of their cancer patients. They are wanting to hear from current and recent patients of their cancer services. Palmerston North Hospital are looking to improve their services and your feedback will help to identify what they are doing well, and what changes may need to be made.

Why Interviews?

I will be doing interviews as part of this research to provide further depth and understanding of your experiences. The information from the interviews and the questionnaires will be combined to understand patient's experiences and to provide recommendations to the hospital.

What will happen from here?

Depending on how many people have shown interest, I may contact you to see if you would like to participate.

I will explain the research to you and answer any questions you may have. If you agree, you will be asked to sign a consent form. The interview can be in person or video call. It will be recorded then typed out without your identifying information attached to it. Once typed, the audio recording will be deleted straight away. Your quotes, and the themes of your story will be used to provide a more in-depth understanding of how supportive care services could be improved, and/or demonstrate how Palmerston North Hospital are doing things well. Only myself and my supervisor will have access to your transcript. Any quotes used will not be identified as coming from you and will be assigned an alias so that those reading recognise the quote as a patient story. If you would like to choose your alias you can do so.

You can also request to see the typed out transcript of your interview and can change anything to better reflect your story. Interviews should take up to 60 minutes and you will receive a \$30 petrol voucher as a thank you for your time.

What are the possible benefits and risks?

There are no expected significant risks with sharing your story, your treatment will not change or differ if you participate or not. It is our hope that this project will benefit patients in the future as MidCentral DHB seek to improve their services.

What are my rights?

You are under no obligation to take part in the interview. If you decide to participate, you have the right to:

- ☐ *decline to answer any particular question;*
- ☐ *withdraw from the study up until you have viewed and approved your transcript. If you do not wish to view your transcript, you may withdraw from the study any time up until 7 days after your interview.*
- ☐ *ask any questions about the study at any time during participation;*
- ☐ *provide information on the understanding that your name will not be used;*
- ☐ *be given access to a summary of the project findings when it is concluded if you request this.*

Contacts

Renee Vitale – Student researcher: Renee.Vitale.1@uni.massey.ac.nz

Dr Don Baken – Supervisor: D.M.Baken@massey.ac.nz

If you want to talk to someone who is not from Midcentral DHB or Massey University, you can contact an independent health and disability advocate on:

Phone: 0800 555 050 Email: advocacy@hdc.org.nz

Māori cultural support

We respect the importance of cultural beliefs and values in research settings and should you require support outside of your own networks then you may wish to contact the Pae Ora Māori Health Service at Palmerston North Hospital for assistance.

Phone: (06) 350 8210 Email: maorihealthunit@midcentraldhb.govt.nz

Psychological support

If sharing your story brings up anything that causes you discomfort and you feel you need support, please contact The Cancer Society supportive care team: Phone - (06) 356 5355

Ngā mihi nui

Renee Vitale

This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern A, Application 20/23. If you have any concerns about the conduct of this research, please contact Dr Negar Partow, Chair, Massey University Human Ethics Committee: Southern A, telephone 04 801 5799 x 63363, email humanethicsoutha@massey.ac.nz.

Appendix H: Participant Interview Consent Form



A review of MidCentral District Health Board's Cancer Services performance against 'He Anga Whakaahuru' - The Supportive Care Framework.

PARTICIPANT INTERVIEW CONSENT FORM

I have read the Information Sheet and have had the details of the study explained to me. My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time.

Please circle:

I agree / do not agree to the interview being sound recorded.

I wish / do not wish to have my recordings returned to me *(Please add your address below if you want your audio recording returned)*.

I wish / do not wish to read my transcript first so that I can make changes to better reflect my story.

I wish / do not wish to receive a summary of the study *(Please add your address below if you want to receive a summary)*.

I agree to participate in this study under the conditions set out in the Information Sheet.

Signature:

Date:

.....

Full Name - printed

.....

**Email or physical
address:**

.....

Appendix I: Massey University Human Ethics Committee Approval



Date: 07 July 2020

Dear Renee Vitale

Re: Ethics Notification - **SOA 20/23 - A review of MidCentral District Health Board's Cancer Services performance against 'He Anga Whakaahuru' - The Supportive Care Framework.**

Thank you for the above application that was considered by the Massey University Human Ethics Committee: **Human Ethics Southern A Committee** at their meeting held on **Tuesday, 7 July, 2020**.

Approval is for three years. If this project has not been completed within three years from the date of this letter, reapproval must be requested.

If the nature, content, location, procedures or personnel of your approved application change, please advise the Secretary of the Committee.

Yours sincerely



Professor Craig Johnson
Chair, Human Ethics Chairs' Committee and Director (Research Ethics)

Appendix J: MidCentral DHB Research Approval



MIDCENTRAL DISTRICT HEALTH BOARD

Te Pae Hauora o Ruahine o Tararua

05 August 2020

Institutional Approval

Phone (06) 350 8061
Fax (06) 355 0616

Postal Address:
PO Box 2056
Palmerston North Central
Palmerston North 4440
New Zealand

Physical Address:
Gate 2
Heretaunga Street
Palmerston North
New Zealand

[Redacted]
[Redacted],
[Redacted]
[Redacted]

Dear Ms Vitale

Re: A review of MidCentral District Health Board's Cancer Services performance against 'He Anga Whakaahuru' - The Supportive Care Framework.

MDHB Research ID: 2020.06.002

The MidCentral DHB Research Support Office would like to thank you for the opportunity to review your study, and has given approval for your research.

Your Institutional approval is dependent on the Research Office having up-to-date information and documentation relating to your research and being kept informed of any changes to your study. It is your responsibility to ensure you have kept Ethics and the Research Office up to date and have the appropriate approvals.

MDHB approval may be withdrawn for your study if you do not keep the Research Office informed of the following:

- Any communication from Ethics Committees, including confirmation of annual ethics renewal
- Any amendment to study documentation
- Study completion, suspension or cancellation

If you have any questions please do not hesitate to contact the Research Support Office.

Yours sincerely

Kelly Butler
Research Support Officer
MidCentral District Health Board

Executive Director, Medical's Office

MidCentral District Health Board, P O Box 2056, Palmerston North 4440
Telephone (06) 350 8036, Email research@midcentraldhb.govt.nz

Appendix K: Māori Research Review Group Approval



**Te Whare Rapuora/Pae Ora
Māori Health Directorate**
PO Box 2056, Palmerston North
Phone (06) 350 8210
Fax (06) 350 8158

23 June 2020

██████████
██████████,
██████████
██████████@midcentral.govt.nz

Study Title: A review of MidCentral District Health Board's Cancer Services performance against 'He Anga Whakaahuru' - The Supportive Care Framework.

MDHB Research ID 2020.06.002

Tēnā koe Renee,

The MidCentral District Health Board (MDHB) Māori Research Review Group considered your research proposal on 23 June 2020.

Thank you for providing the documentation relating to this project.

Comments:

- We commend you for your consideration and consultation with relevant people about how best to encourage and support Māori participation in this research.
- In your Patient Information Sheets under the question "What are the possible benefits and risks?" we suggest that you amend the beginning sentence so it refers to "...no significant expected risks..." as it is rare that there are no risks at all, even in low-risk research projects.
- We note that you have yet to add the Ethics Committee statement to your participant information sheets.
- We suggest that you add a few words in your Participant Information Sheets to ensure that any participants wanting to access additional cultural support are aware that the Pae Ora Māori Health Service is based at the Palmerston North Hospital. For example, you could expand the existing sentence to say "...you may wish to contact the Pae Ora Māori Health Service at the Palmerston North Hospital for assistance."
- It is suggested that you may wish to add an "Other" option with room to add free text to question 4 ("How were you diagnosed?") of the patient questionnaire as there may be other possible sources of diagnosis. In a similar way, you may also wish to add an "Other" option to

NB. The views expressed in this document are those of the Māori Research Review Group, Pae Ora Paiaka Whaiora Hauora Māori Directorate, MidCentral Health.



**Te Whare Rapuora/Pae Ora
Māori Health Directorate**

PO Box 2056, Palmerston North

Phone (06) 350 8210

Fax (06) 350 8158

question 4 (What is your role?) in the staff questionnaire in case there is a participating staff member who does not feel that they belong to one of the specified groups (e.g. spiritual care provider, non-clinical manager etc).

- The MDHB Māori Research Review Group would be willing to assist in the dissemination of your findings to appropriate Māori organisations, Māori health professionals and/or Māori researchers in the MidCentral district if this is required.

On behalf of the MidCentral District Health Board Māori Research Review Group the study has been endorsed to commence at this DHB.

This endorsement by the Māori Research Review Group is dependent on the MDHB Research Office having up-to-date information and documentation relating to your research and being kept informed of any changes to your study. It is your responsibility to ensure all relevant groups (e.g. ethics committees, MDHB research office) have access to current and accurate information about the study and that all of the appropriate approvals are in place throughout the duration of your research.

We wish you well with your research.

Whaowhia te kete mātauranga
Fill the basket of knowledge.

Nāku noa, nā

On behalf of the Māori Research Review Group

Dr Janine Stevens FNZCPHM

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NB. The views expressed in this document are those of the Māori Research Review Group, Pae Ora Paiaka Whaiora Hauora Māori Directorate, MidCentral Health.

Appendix L: Breakdown of Likert Responses – Staff Survey

Staff Survey Results

Question	Agree		Somewhat Agree		Somewhat Disagree		Disagree		Total	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
1. The environment in which I interact with patients meets their privacy needs.	15	35.7	14	33.3	9	21.4	4	9.5	42	100
2. The environment in which I interact with patients meets their cultural needs.	4	9.5	24	57.1	12	28.6	2	4.8	42	100
3. When I interact with a patient, and their whanau we have enough time scheduled to discuss what is important to them.	8	19.5	21	51.2	6	14.6	6	14.6	41	100
4. I have the required experience and skills to handle difficult conversations (such as giving bad news).	15	41.7	13	36.1	6	16.7	2	5.6	36	100
5. I am supported by MidCentral Health to reflect on situations of difficult communication.	7	18.4	15	39.5	8	21.1	8	21.1	38	100
6. I know how to use / access interpreter services if required.	23	56.1	16	39.0	1	2.4	1	2.4	41	100
7. I have sufficient understanding of the impact of social needs on my patients and their whanau.	18	41.7	19	36.1	3	16.7	1	5.7	36	100
8. I know how to use evidence-based tools or screening methods to assist in identifying and clarifying social needs of my patients.	6	15.4	16	41.0	7	17.9	10	25.6	39	100
9. I have sufficient understanding of the psychological impact of cancer on my patients and their whānau.	21	51.2	19	46.3	0	0.0	1	2.4	41	100
10. I know how to use evidence-based tools or screening methods to assist in identifying and clarifying psychological needs of my patients.	7	17.9	21	53.8	9	23.1	2	5.1	39	100
11. There is a culture of whānau inclusion in services provided to our patients.	13	31.7	24	58.5	3	7.3	1	2.4	41	100
12. Systems are in place to ensure patients and their whanau are fully informed of their right to be cared for in a manner which is in agreement with their spiritual beliefs.	8	21.1	26	68.4	3	7.9	1	2.6	38	100

Appendix M: Breakdown of Likert Responses – Patient Survey

Patient Survey Results

Question	Agree %	Somewhat Agree %	Somewhat Disagree %	Disagree %	Total %
1. I was involved in my treatment and care decisions.	93.1	6.9	0.0	0.0	100
2. My family/whanau were able to be involved in my treatment and care decisions as I wished.	9.5	57.1	28.6	4.8	100
3. Myself and my family/whānau were linked to services when needed which were able to support my cultural and spiritual needs.	63.6	31.8	4.5	0.0	100
4. The place in which I had conversations with health care professionals about my condition, wellbeing or treatment met my needs for privacy .	80.0	13.3	0.0	6.7	100
5. The place in which I had conversations about my condition, wellbeing or treatment met my cultural needs.	77.8	16.7	0.00	5.6	100
6. The place in which I received my treatments met my privacy needs.	85.7	7.1	7.1	0.0	100
7. The people involved in my care had the time to discuss my concerns fully with me and my family/whanau.	81.5%	11.1	3.7	3.7	100
8. I found information resources and services relevant (in their content, format and how it was shared) to my cultural needs.	83.3	11.1	5.6	0.0	100
9. My social support needs were considered and addressed throughout my care.	63.0	18.5	11.1	7.4	100
10. My psychological (emotional) needs were considered and addressed throughout my care.	62.1	13.8	10.3	13.8	100
11. I was informed of my rights to be cared for in a manner which is in agreement with my spiritual beliefs.	76.5	5.9	5.9	11.8	100
12. My spiritual needs were considered and addressed throughout my care.	62.5	18.8	6.3	12.5	100
13. I was well informed of the process when I moved from treatment to follow up.	71.4	17.9	7.1	3.6	100
14. My rehabilitative needs were assessed, and I was referred appropriately if needed.	70.8	20.8	8.3	0.0	100
15. I was well informed of the supportive care services available to me.	63.0	22.2	11.1	3.7	100